University of Cape Town

Department of Health and Rehabilitation Sciences

Disability Studies Division

Full Dissertation

Master of Philosophy in Disability Studies

Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya

Rachael Wachera Wanjagua

Student Number: WNJRAC001

Supervisor: Dr Judith McKenzie

DECLARATION

I, Rachael Wachera Wanjagua, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate……

Date: 10th May 2018…….

ACKNOWLEDGEMENTS

I dedicate the work in this study to all parents, caregivers, and my friends with intellectual disability who I have met in the course of my work and life's journey. I feel indebted to you for how you have shaped the way I see things and continue to inspire others in your silent ways. It is a paradox that, while you are not considered intellectual, you inspire a lot to learn in deeply intellectual ways. My hope is that this work, simple as it is, begins another of your journeys where your needs are considered as important as of those around you.

Without the support of my dear mother, Ejidiah Muthoni, and sister, Naomi Njeri, I would barely have achieved anything. I'm deeply grateful for your believing in my cause and supporting me emotionally, spiritually, financially and with everything else you could do to make this a reality and a success. To both of you, my beloved mother and sister, I'm eternally grateful. May God bless your kindness, not just to me but to the ones for whom this work is dedicated with eternal joy.

To the family of Judy and Andrew who willingly opened their doors for me while I was in Cape Town, your support was edifying. Thank you for your warmth and friendship.

I'm also grateful to the University of Cape Town for the scholarship that made it possible for me to register in 2017.

Finally, to my supervisor, Dr Judith, who has encouraged me throughout the process and helped my small feet stand somewhere in the shadows where giants stand. It has been a pleasure to listen to and be mentored by you.

I'm grateful to myself for pushing through this wild jungle even when all seemed impossible. May God be praised for His providence and wonderful work.

ABSTRACT

Intellectual disability (ID) is associated with limitations in cognitive, practical and adaptive functions. Individualised supports therefore enhance functioning for people with ID. Families often manage supports for their ID members alone. If not supported, the family quality of life (FQOL) is affected, which also affects the quality of life of the disabled member. FQOL therefore is an outcome measure for support services and strategies. In Kenya, FQOL and supports of families with individuals with ID is not known. This **study's purpose** was to understand the FQOL of people with ID and their families and their support needs. The **methodology** used was a qualitative design, exploring perceptions of 7 people with mild ID and 8 caregivers on FQOL and support needs through interviews and 2 focus group discussions (FGDs). The Beach Centre Family Quality of Life Conversation Guide was used and piloted with 2 people with ID and 2 caregivers. It was adapted by simplifying the questions for people with ID and translated into Swahili. The study had emancipatory approaches with 2 people with ID and 1 caregiver as research assistants. 10 participants were identified through special schools and a village elder from each zone namely Nyahururu, Kinamba, Ol'ngarua and Mailoinya in Laikipia County. 2 participants for each category were selected through **random sampling**. **Informed consent** was received from all participants and caregivers of people with ID. Ethical approval was granted by the Human Research Ethics Committee of the University of Cape Town and a research permit granted by the Kenya National Commission of Science, Technology and Innovation. **Data** was **collected** and recorded on a mobile device. Identification codes were used to protect anonymity. Verbatim data was transcribed and checked by participants in FGDs. Confirmed data was translated into English and **deductive** and **inductive analysis** was done using Dedoose version 7.5.15. Similar data from the 5 domains in the Beach Centre FQOL Conversation Guide was coded together to develop the theme (community supports). **Findings**- FQOL in Kenya can be described through family interaction, parenting, emotional wellbeing, disability-related supports, physical/material wellbeing and community supports. Poverty, rights of people with ID and cultural constructions of disability can inform disability-related services, government policies and guidelines. **Study limitations**: The findings are representative of support needs for families of people with mild ID. The study gathered perspectives of people with ID and caregivers, and hence more views could be gathered from other family members. This study was conducted in rural settings and should be interpreted with this in mind.

CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AAIDD	American Association of Intellectual and Developmental Disabilities
APA	American Psychiatric Association
CG	Caregivers
DSM	Diagnostic and Statistical Manual
FGD	Focus Group Discussion
FQOL	Family Quality of Life
HREC	Human Research Ethics Committee
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
ICD	International Classification of Disease
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
KSMH	Kenya Society for the Mentally Handicapped
LMIC	Low- and Middle-Income Countries
NACOSTI	National Commission of Science, Technology and Innovation
NCPWD	National Council for People with Disability in Kenya
PWID	People with Intellectual Disability
UNCRPD	United Nations Convention on the Rights of Persons with Disability
WHO	World Health Organization

1 CHAPTER 1: INTRODUCTION

1.1 Intellectual disability in Kenya

Globally it is estimated that 10.4/1000 children and young adults have intellectual disability (ID). The majority of them hail from low- and middle-income countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Currently, there are no statistics about how many people have ID in Kenya, however, the Kenya Society for the Mentally Handicapped (KSMH) estimates that 3.6 million Kenyans have some form of ID and/or mental health condition (KSMH, 2014). The estimate combines both people with ID and those with mental health issues and illustrates the generally poor understanding of ID relative to mental health. As such, planning intervention is poorly established in the country.

1.2 Family experiences

Disability is a highly stigmatised issue in most Kenyan communities. People with ID are often isolated from mainstream society. Families of people with ID often get excluded from extended family relations. A case scenario is in Laikipia County where I grew up and worked with disabled people and their families. Laikipia is 200km North of Nairobi the capital of Kenya. It is a rural and remote area and majority of the families were materially poor. In Laikipia, the struggle with stigma and supports for members with ID was visible, and in some instances, families abandoned care of their members. Families also often broke up on the account of having a child with disability. Most of the time, mothers were left alone to care for the disabled children. It was common to find people with ID strolling alone in the community, borrowing food or seeking company. Most of the time they were hardly well-groomed and there was evidence of neglect, such as being malnourished, poorly dressed, poor hygiene, and this contributed to further isolation from community members. Cases of sexual abuse and violence were rampant, often owing to gullibility (being used to participate in crime) of people with ID.

1.3 My experience working with people with intellectual and developmental disorders in Kenya

For 12 years I worked with people with disabilities and their families in parts of Nyandarua and Laikipia districts in Kenya. This experience exposed me particularly to the reality of the challenges faced by people with ID and their families in their day-to-day lives. The programme that I worked for offered supports with physiotherapy, education and vocational training to people with intellectual and other developmental impairments. There were very few special units

in schools. Most of the time, a class comprised of individuals with different impairments and one teacher to manage the class. The diversity of special needs in a class necessitated that a teacher concentrated more on providing basic reading and writing skills and activities of daily living. The children and young adults did not receive formal education and the time in classrooms was spent learning the alphabet, singing or counting. It did not matter the level of impairment or abilities one had. In my opinion, this affected the quality of education for individuals with intellectual and developmental disabilities as well as their educational outcomes which in turn had an influence on their quality of life. The schools would have two or three support staff who were poorly paid (approximately 30 US dollars per month) and were tasked with all the needs children with disability required, such as cooking, feeding, bathing, laundry, cleaning, accompanying to the hospital, and any social support required by the disabled children in school. What I observed is that teachers also ended up providing caretaking responsibilities as it was not humanly possible for the support workers to provide all the required supports. I also observed that people with ID neither got employed after school nor did the majority of them go for training towards a specific job, as they were mostly viewed as incapable of learning and working by community members.

1.4 A different experience living with people with intellectual disability in Kenya

After 12 years of working in the community with disabled people and challenged by the seemingly vulnerable situation of people with ID and their families, the organisation I worked for decided to start a L'Arche community. L'Arche is an international federation of communities around the world that welcome people with and without ID to share life in small family-like setups. The mission of L'Arche is to make known the gifts of people with ID by empowering them within their communities. This is done through promoting a culture of responding to the different needs of intellectually disabled members while also recognising their contribution in enhancing integral human growth (L'Arche Internationale, 2016).

As at 2015, L'Arche in Nyahururu had welcomed 20 people with ID who lived with their families to participate in day programmes and 10 people with ID who were welcomed into two L'Arche homes where they shared in daily life with assistants who supported them with various needs (L'Arche Kenya & St Martin Communities, 2014). I lived in this community for eight years and the experience gave me a different perspective of intellectually disabled persons and conviction regarding the benefits of supports and relationships in improving their quality of life.

In L'Arche, we carried out daily activities together with people with ID in the house and supported them to work in sheltered workshops and the community. Special focus was given to facilitating having choices, being respected, autonomy, participating in community activities and events, self-representation, and mutual relationships integrated within activities of daily living. A lot of advocacy was done in the churches, schools and community to have the disabled members integrate and to change negative perceptions of disability within society. The members with ID developed meaningful relationships with other members of society, became happier and had increased self-esteem. The transformation in the lives of the individuals with ID had a positive impact on the way community members viewed people with ID when they were given the right supports (L'Arche Kenya & St Martin Communities, 2014).

I was aware that there were many people with ID still living in deprivation, without opportunities for them to live their full potential, notwithstanding how their families struggled alone without supports. The isolated struggle of families and individuals with ID who desired a decent life, recognition as full members of society and belonging led to consideration of conducting this study with an aim to discovering with families collectively what could lead to a more fulfilling life.

1.5 The meaning and importance of the supports paradigm in intellectual disability

The focus of this study was around supports for people with ID and their families because of all the difference it makes in their quality of life. Support in its literal sense means to offer assistance, encouragement or approval. In the context of supports for people with ID, it is considered to mean active involvement and concern for success in living lives fully and achieving personal independence as much as possible (Thompson et al., 2009). For people with ID, supports have been seen to improve their functioning (Schalock, Luckasson, & Shogren, 2007). The supports paradigm has extended the conceptualisation of ID as limitations in conceptual, practical and adaptive skills which supports mitigate. Supports have people with ID to gain milestones in self-determination, work, equal opportunities, relief for families and have counted in enhancement of individual and family quality of life (FQOL). FQOL measures therefore have been lauded as good indicators of support outcomes (Schalock et al., 2007; Thompson et al., 2009; Luckasson & Schalock, 2013).

Apart from the benefits of providing individualised supports, understanding supports for people with ID has contributed to a greater understanding of the construct of ID. Rather than looking at ID as an individual problem that needs to be fixed (intervening at the biological level), the supports construct has shifted the understanding to the contextual and environmental factors (social, cultural, economic, political and physical factors) that contribute to the disability experience hence requiring to be acted on (WHO, 2001). This has contributed to the redefinition of ID to include aspects of adaptive behaviour which were not initially considered on an equal basis with intelligence quotients (Luckasson & Schalock, 2013).

Supports for people with ID and their families is not common practice in Kenya. There is an underlying assumption that people with ID should just fit into daily activities like any other person. This becomes a challenge for people with ID who cannot compete on an even footing with other societal members without supports. There is also little attention to the plight of people with ID and their families due to silence around advocacy. Limited knowledge around the essence of supports for people with ID and their families in Kenya forms the basis of this study to determine what their FQOL is and the supports they require for their wellbeing.

1.6 Measuring family quality of life

The most common FQOL measures being used in the field of ID are the Family Quality of Life survey (FQOLS-2006) developed by (Isaacs et al., 2007) and the Beach Centre FQOL scale developed by the Beach Centre on Disability (Park et al., 2003; Poston et al., 2003; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). FQOLS-2006 has 54 items which have two qualitative measures (attainment and satisfaction) and four quantitative measures (importance, opportunities, initiative and stability). FQOLS-2006 measures nine domains: health of family, financial wellbeing, family relationships, support from others, support from disability services, influence of values, careers and preparing for careers, leisure, and community involvement.

The Beach Centre FQOL has 25 items which measure satisfaction and priority of supports in five domains of family interaction, parenting, emotional wellbeing, physical/material conditions, and disability-related supports. The Beach Centre FQOL is the preferred measure for this study because it has a qualitative approach and is easier to use with participants who have ID. It has mainly been used in developed countries, and in Africa, it was validated for use in the Democratic Republic of Congo (Aldersey Francis, Haines, & Chiu, 2017).

1.7 Significance of the study

Little is known about FQOL in families of people with ID in low-income countries. Services and support interventions are not available and generally there is a poor understanding of the ID construct (Mercier, Saxena, Lecomte, Cumbrera, & Harnois, 2008). What is apparent is that operationalising supports for people with ID and families in developed countries has contributed to improved FQOL but has also led to a better understanding of ID. People with ID have experienced disability to a greater or lesser degree depending on the supports they received (Luckasson & Schalock, 2013). Focussing on supports has shifted the perception of treating cognitive limitations as the main issue to be fixed in people with ID to environmental and contextual factors that need to be fixed for their development. This development is consistent with the social model of disability which views disability as not inherent in the individual but as also influenced by determinants external to the individual (Thompson et al., 2009). Understanding support needs for people with ID and families in Kenya can improve the conceptualisation of ID in the country, contribute to dissipating the negative meanings attributed to people with ID and their families, as well as improve the quality of lives of families of individuals with ID. By understanding support needs, existing formal and informal support structures can be strengthened to ensure stability and bridge the gap of inequality that exists in the lives of people with ID in Kenya. FQOL and knowledge of required supports can contribute to policy development in Kenya to ensure that people with ID and their families receive supports, and that sufficient resources are allocated by government and civil societies to safeguard their wellbeing.

1.8 Purpose of study

The purpose of this study is to contribute to the understanding of FQOL of families of people with ID in Kenya and their support needs.

1.9 Aim of study

The aim of this research is to explore perceptions of individuals with ID and their caregivers regarding their FQOL in Kenya as well as identifying their support needs.

1.10 Research questions

1. What is the FQOL as perceived by people with ID and their parents/caregivers in Nyahururu?

2. What are the perceived support needs of people with ID and their parents/caregivers in Nyahururu?

1.11 Study objectives

1. To describe the FQOL of people with ID and their parents/caregivers in Nyahururu.
2. To establish the support needs for people with ID and their parents/caregivers in Nyahururu

1.12 Overview of thesis

This thesis is divided into 6 chapters: introduction, literature review, methodology, data analysis, discussion and recommendations. Chapter 2 is a discussion of the theoretical framework of this study which gives an understanding of the construct of ID and the way it relates to FQOL, and the supports paradigm and its relation to an ethics of care. These concepts are discussed as informed by literature on the role of supports for people with ID and their families. It details the FQOL experiences of family members and individuals with ID mainly from a global perspective as there are few studies around the same topic carried out from low-income countries.

Chapter 3 is an elaborate description of the qualitative nature of the study methodology incorporating emancipatory methods by having individuals with ID and caregivers as co-researchers and participants. This method was chosen to give weight to findings of this study and give voice particularly to participants themselves, as well as to empower the study participants during the research process. All the study processes are discussed in the chapter, including ethical considerations and approvals.

Chapter 4 is an inductive and deductive analysis of the views of caregivers and people with ID regarding their FQOL. The FQOL themes and sub-themes are presented. Expressed support needs by people with ID and caregivers are also presented.

Chapter 5 is a discussion of the outcomes of the study as the main FQOL domains from the Kenyan context. The findings are consistent with the FQOL domains in the Beach Centre FQOL, and community supports and cultural values were seen to further contribute to FQOL in Kenya. The discussion is an integration of participants' views of FQOL and supports with disability theories, cultural understanding and knowledge from the paradigm of FQOL in ID from literature. What becomes apparent in the Kenyan setting is that the community has a role to play

in determining the FQOL manifested in culture and traditions. These factors are a traditional ethic of *ubuntu* and may go a long way to emancipating people with ID and their families in society, but some cultural beliefs detract from this. This finding highlights the need to advocate for harnessing the positive cultural and community values of *ubuntu* and an ethics of care in support for people with ID and their families which in the long run can be sustainable ways of providing supports in low and middle-income settings.

Chapter 6 is a presentation of recommendations for support systems and strategies by individuals with ID and caregivers. Due to the inequality people with ID face in the community, further recommendations on policy development, legislation and advocacy are made.

2 CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The aim of this research was to investigate the family quality of life (FQOL) of people with intellectual disability (ID) and their families in Kenya in order to establish their needs for supports. This chapter is an exploration of the global and local understanding of the ID construct, individual and FQOL and the supports paradigm in the field of intellectual and developmental disorders. The theoretical framework is based on an understanding of ID which recognises the role played by supports to reduce the disability experience. Supports are informed by individual and FQOL. Supports which improve functioning have a relationship with ethics of care. Ethics of care ensures dignity is accorded to individuals with ID and their families in the process of providing supports. The way culture understands ID and supports determines the attitude communities uphold and has an influence on the FQOL. These constructs are discussed in detail below.

2.2 Literature search

A search of the literature was done on Ebscohost, JSTOR, Scopus and Science Direct databases which were accessed through the University of Cape Town libraries as well as from bibliographies in some articles. Different searches were done using the keywords “intellectual disability and quality of life”, “intellectual disability and family quality of life” and “intellectual disability and support”. Boolean phrases to keywords like “intellectual disability”, “mental retardation”, “learning disability”, “developmental disability” or “learning disabilities” were used. For quality of life, the Boolean phrases used included “wellbeing” or “well-being”. Literature was also used from websites of the World Health Organization (WHO), United Nations (UN), Kenyatta University, Nairobi University, National Council for People with Disability in Kenya (NCPWD), American Association of Intellectual and Developmental Disabilities (AAIDD), American Psychiatric Association (APA), Beach Centre of Kansas University, and the ARC for people with intellectual and developmental disabilities. A total of 531 articles were found to be of relevance to this study. Some articles were also retrieved from bibliographies of important studies. The following is a discussion of the reviewed literature.

2.3 Understanding Intellectual Disability

This study's main focus is on the lives of people with ID. I begin with a brief overview of understanding the ID construct. This will involve understanding the current terminologies being used, and how the conceptual framework contributes to the understanding of ID. This understanding of ID strengthens the theoretical framework that envisions supports as contributing to a good FQOL for people with ID and their families.

The recent Diagnostic and Statistical Manual edition five (DSM 5) of the APA classifies ID under neurodevelopmental disorders (APA, 2013). It has been classified as such due to the understanding that ID has its onset during the developmental period affecting brain development before, during and after birth, therefore affecting an individual across their lifespan (APA, 2013; Bertelli, Munir, Harris, & Salvador-Carulla, 2016). The disorder is characterised by deficits in general mental abilities (i.e. reasoning, problem solving, planning, abstract thinking, judgement, academic and experiential learning). These deficits result in limitations in adaptive functioning, which includes personal independence at home or in the community and social responsibility in the areas of communication, social, academic or occupational participation (Holdnack, Zhou, Larrabee, Millis, & Salthouse, 2011; APA, 2013).

This definition of ID, however, differs from an earlier conceptualisation by the American Association of Intellectual and Developmental Disability (AAIDD) which argues that a lack of supports for a person with ID contributes to disability because it limits function (Luckasson et al., 2002). Attributing ID solely to limitations of the developing brain takes a medical model perspective. This perspective informs treatment or management mostly towards only improving cognitive functions and remains blind to how a lack of supports contributes towards these limitations (Bertelli et al., 2016). According to Schalock et al. (2007), human functioning is enabled by an interaction of the individual with the environment, which, with ID, is enhanced by supports. The multidimensionality of human functioning has been reiterated to include intellectual ability, health and adaptive functions (Wehmeyer et al., 2008). For this reason, AAIDD is of the opinion that ID is a disorder associated with limitations in adaptive behaviour (conceptual, practical and adaptive skills) not just caused by cognitive deficits but a lack of supports in these functions as well (Luckasson et al., 2002; Schalock et al., 2007; Schalock et al., 2010; Tassé, Luckasson & Nygren, 2013). Conceptual skills involve language, literacy, money, time, number concepts and self-direction. Social and adaptive skills which are used

interchangeably in the literature include interpersonal interaction, social responsibility, self-esteem, social intelligence, social problem solving, and ability to follow rules, obey laws, and avoid victimisation. Practical skills involve personal care activities, occupational skills, health care, travel and transportation, schedules and routines, safety, and use of money and telephones (Schalock et al., 2010). The essence of supports is introduced in this definition as an important measure that either facilitates function or the lack of it, resulting in disabling experiences.

Tassé, Luckasson and Schalock (2016) emphasise the need to recognise cognitive functions and adaptive behaviour not as causally linked but as equal and independent features in the diagnosis of ID. The importance of adaptive behaviour makes the social and environmental influence on individual functioning significant (Shakespeare, 2006; Schalock et al., 2007; Luckasson & Schalock, 2013). This classification is in line with the International Classification of Functioning, Disability and Health (ICF) that views disability as an interaction between the individual and the environment (WHO, 2001). The understanding is that ID is not a static state but manifests in variations over different life stages. It is influenced by learning and acquisition of skills, social interaction, and biological, environmental and personal factors (Bertelli et al., 2016).

As the International Classification of Disease (ICD-11) is under review and needs to be consistent with the new revisions of ID, it proposes a new classification of ID as a health condition (Intellectual developmental disorder-intellectual disability) and as a disability (Intellectual Disability-ID) (Bertelli et al., 2016). This follows an understanding of the multidimensionality of the condition which requires significant attention in both health and disability aspects (APA, 2013; Bertelli et al., 2016; Tassé, Luckasson & Schalock, 2016). The classification will be important because it will help to guide interventions in the health paradigm, and research priorities and interventions in social, economic and political dimensions around ID, which Bertelli et al (2016) argue were not as conspicuous in the past.

In summary, all the classifications and definitions of intellectual and developmental disability lead to the overall understanding that the individual with ID has significant cognitive limitations. Environmental factors can increase the disability experience in ID if supports are not provided to enhance adaptive functions of an individual. This understanding highlights the necessity of

considering cognitive factors as well as environmental factors impacting on an individual with ID for effective intervention programmes.

2.3.1 Diagnosing intellectual disability

Clinical diagnosis of ID historically relied on the measure of Intelligence Quotient (IQ). Standardised psychometric tests would be done to measure memory, writing, arithmetic, spatial recognition and analytical thinking. An IQ of below 70 would be considered as having ID (Sternberg, 1988).

With the advent of adaptive abilities being considered on an equal basis with cognitive functions to determine ID, it is now a prerequisite to measure adaptive functions (conceptual, practical and adaptive skills) as well. The tests should be culturally, environmentally and age appropriate (Tassé et al., 2013). Adaptive functions are considered the sum of two standard deviations below the mean for each conceptual, practical and adaptive skills set (Schalock et al., 2010; Greenspan & Woods, 2014).

The severity of ID is classified as a component of the adaptive functions. The extent of difficulty an individual has in conceptual, social and practical skills varies across individuals and is clinically categorised as either mild, moderate, severe or profound (Salvador-Carulla et al., 2011; APA, 2013; Tassé et al., 2013). Research shows that mild ID has the highest prevalence (Stromme & Valvatne, 1998; Heikura et al., 2003).

ID may also present with associated problems such as epilepsy, problematic behaviour, and physical and mental health conditions (Felce et al., 2008). According to Maulik et al. (2011), the prevalence of ID globally is estimated to be 10.4/1000 with children and adolescents from low- and middle-income countries (LMICs) being more affected. Kenya lacks data regarding prevalence of people with ID which could be attributed to a lack of measurement tools that are context specific for IQ and adaptive behaviour tests. Diagnosis of ID in Kenya is based on developmental delay and observed cognitive limitations by clinicians making it remain highly medicalized even pertaining interventions.

2.3.2 Supports paradigm for people with intellectual disability

Schalock et al. (2007) highlighted the significant role played by supports to determine human functioning. This role is understood in the context of how supports improve adaptive function for individuals with ID (Schalock et al., 2007; Buntinx & Schalock, 2010; Schalock et al., 2010;

Schalock, 2011; Luckasson & Schalock, 2013). Similarly, Shogren et al. (2009) argue that when supports are developed into individualised support plans, it enables people with ID to make choices, self-advocate, and increase autonomy and self-determination, leading to an enhanced personal quality of life. Basically, the social, cultural, political, economic and legislative contexts in which people with ID find themselves are considered in determining the extent of disability (Schalock et al., 2010).

The supports paradigm has highlighted the unequal position of people with ID in society (Luckasson et al., 2002; Thompson et al., 2009). Supports have been defined as the strategies and services that empower, develop, educate and integrate people with ID into society to improve their wellbeing by acting on the personal and environmental factors causing the experience of disability (Buntinx, 2003; Thompson et al., 2009; Zuna et al., 2010). Studies done in high-income countries show that supports frameworks established at individual, family, societal and national levels help to shape and guide services and resource allocation (Thompson et al., 2009; Luckasson & Schalock, 2013). At individual and family levels, supports include person-centred planning, respite care and supported living arrangements (Schalock et al., 2010). Families have been targeted in the supports paradigm as the environments that facilitate functioning for individuals with ID. Thus, it is not only the individual that needs supports but also their families. Family support is the provision of goods and services, protection, subsidies, funding or professional support among others to a family which has a member with ID living at home (Turnbull, Summers, Lee & Kyzar, 2007).

Supports also help to improve inclusion and integration of individuals with ID and their families at the community level. Supports have therefore targeted strategies at the community level to include community-based services, social inclusion plans and agency. Such strategies provide families with important information and direct supports for individuals with ID, and link families with government agencies and advocacy, among others (Chadwick et al., 2013). Some of the cited supports for families of individuals with ID include respite or out-of-home care, advocacy, nurturing of life skills, and social, psychological and health-related supports (Summers et al., 2005; Chou, Tzou, Pu, Kröger, & Lee, 2007; Burton-Smith, Mcvilly, Yazbeck, Parmenter, & Tsutsui, 2009; Werner, Edwards & Baum, 2009; Brown, Geider, Primrose, & Jokinen, 2011; IASSIDD, 2013).

The sociocultural adaptations of a society influence supports for people with ID and their families. For example, societies that promote autonomy and independence are seen to provide less support than societies that promote interdependence and collectivism (Boehm & Carter, 2016). Some of the supports at the societal level include education, for example in providing teacher aides, psychologists and specialised teachers, advocacy, and professional services such as rehabilitation and social supports, which increases social inclusion and friendships among people with ID and members of the wider society (Bramston, Chipuer & Pretty, 2005; Stancliffe, Jones, Mansell & Lowe, 2008). Support within social networks offers peers an opportunity to interact with people with ID which reduces the notion that it is difficult to relate with them, while at the same time providing relief from caregiving tasks in families. Social inclusion also provides opportunities to people with ID and their families to engage in other personal interests, which has been associated with psychological wellbeing (Kroese, Hussein, Clifford & Ahmed, 2002).

At a national level, support services have included advocacy, legislation, development of policies, and implementation, monitoring and evaluation of service outcomes (Shogren et al., 2009). Effective policies that are based on evidence have provided guidance for service providers and improved individual and FQOL outcomes (Summers et al., 2005; Arc, 2009; Turnbull & Stowe, 2014). For example, employment is seen to increase social networks of people with ID. It also changes negative perceptions about abilities of people with ID (Grech, 2011; Foley et al., 2014; Kavanagh et al., 2015). Success in operationalising support frameworks has been achieved where there was collaboration between people with ID, family members, policy makers, service providers and the state so that there is self-presentation and determination (Sonpal & Kumar, 2012; Turnbull & Stowe, 2014). Such support models are seen as good practice and align with international guidelines, such as the ICF, that look at the overall individual and contextual factors influencing wellbeing (WHO, 2001; Salvador-Carulla et al., 2011). However, the provision of supports varies across different global contexts.

The World Health Organization Atlas of Intellectual Disability (WHO Atlas ID) report indicates a significant lack of concern of issues regarding ID globally. There are few policies and legislation regarding people with ID globally but most significantly in LMICs (Mercier et al., 2008). The lack of policy is attributed to low visibility of issues concerning people with ID, resulting in low priority accorded by governments (Samuel, Leroy, Hobden & Lacey, 2012).

The most striking differences between high- and low-income countries in the World Atlas ID are in access to information, legislation, government benefits, financing and availability of services (Mercier et al., 2008). The majority of high-income countries address education, health, disability pension, social security, subsidies for food, housing, transport, medication, direct payments for specific purposes, and tax or fiscal benefits and social welfare, most of which are financed through taxes, non-governmental organisations (NGOs) or self-support by the family. Stakeholders involved in providing supports in high-income countries include special educators, social workers, psychiatrists, psychologists, teachers and primary health care workers. Of these professionals, the majority receive in-service training with few receiving training at a graduate level. This indicates the low level of importance issues of supports for individuals with ID are given even in developed countries (Mercier et al., 2008).

The WHO Atlas ID also notes a lack of published studies on ID in Africa. Some of the studies conducted mainly focus on conceptualisation of disability where ID is viewed as contrasting from what is considered 'normative' (Njenga, 2009; Gona et al., 2011; Mannan, 2014;). The epistemological foundation of this perception stems from indigenous knowledge, cultural constructions of disability, and belief systems. In most studies, disability is perceived to be caused by supernatural forces such as witchcraft, God's will, curses, punishment, inappropriate family relations and medical factors to some extent (Njenga, 2009; Berghs, Dos & Zingale, 2011; Gona et al., 2011). These conceptualisations contribute to discrimination and stigma associated with disability in the African context leading to social exclusion (Mannan, 2014). In countries like Kenya, a lack of support services is associated with a lack of focus by government on issues pertaining to ID as well as stigma. Negative attitudes by society results in people with ID suffering negligence and poor education, with a resultant poor development of skills with consequent exclusion from employment and development opportunities (Njenga, 2009; Njagi, 2015; Maina, 2016; Koros & Harrahs, 2017).

Mercier et al. (2008) further note that in many low-income countries, poor outcomes of services for people with ID are as a result of issues concerning people with ID being scattered throughout various government departments, which poses challenges to planning, implementation and monitoring. Financial support from government and NGOs in low-income countries is reportedly low or lacking. Whenever present, it mostly supports education, rehabilitation, self-help support,

empowerment, and provision of direct services (Mercier et al., 2008). However, many of the support services provided by aid agencies do not last after the exit of the organisation, which is partly attributed to colonial legacies that create dependency and notions of victimhood among the populations they intervene in (Berghs et al., 2011; Chataika, Kallon, Mji, & MacLachlan, 2011). Consequently, populations of people with disabilities are disempowered to advocate for political and social changes that would change their situation. Ignorance around issues of ID contributes to failure by families and society to make the necessary accommodations for individuals with ID to fit in various social environments (Musima, 2014).

With provisions for supports for people with ID enshrined in the Disability Act (2003) of Kenya as a constitutional right, perspectives of caregivers and individuals with ID in Kenya regarding the needs and nature of supports they require would be of benefit to inform relevant support systems at the family, community and national levels. However, putting in place programmes that assist people with ID and their families to function requires a step further to ensure they are part of society and contribute to its growth like other citizens. This aspect has not been achieved through a rights approach. Relationships stemming from care arrangements, however, begin to reveal important paradigms in this field.

2.4 Ethics of care

Given that ID is a lifelong condition and sometimes the individual with ID has associated problematic behaviour, care has sometimes been characterised as daunting, stressful and challenging (Markey, 2000; Kim & Turnbull, 2004; Sandy, Kgole & Mavundla, 2013). As such, intellectual impairment has been viewed as reducing quality of life of individuals and their families. Justification for elimination of people with ID through genetic determination has been supported in a bid to 'rid' families of the burden of care and a poor quality of life (Kuhse & Singer, 1985). Carlson and Kittay (2009) and Woodcock (2009) argue that such negative epistemological perceptions of ID manifest in current debates around existence, moral status and speciesm, undermining the worth of individuals with ID.

As such, Kasnitz and Shuttleworth (2001) argue that when caregiving is regarded as burdensome, individuals with ID are disadvantaged because they are viewed as contributing to poor quality of life. The result of discrimination is seen in a lack of opportunities to people with

disability in the guise of having bad bodily difference, which has negative social and economic impacts on them (Barnes, 1995; Whyte, 1995; Shakespeare, 2006)

It is such implications that have sparked necessity in debates around care in the field of ID in trying to unearth the dynamics of caregiving relationships and the consequences they hold. Caregiving and supports provide dignity and contribute to the realisation of individual rights for people with ID (Thompson et al., 2009).

Kittay (2011) argues that ethics of care is an expression of human dignity which benefits both the individual being cared for and the care provider. Some studies have established from caregivers that caregiving has a positive transformational effect in cultivating values such as warmth, tenderness and trust. Carlson and Kittay (2009) report that meaningful relationships which occur in the practice of caregiving have the benefit of bringing about cohesion in society despite lacking economic benefits. This contrasts with perspectives of societies that are inclined to judge benefit through the lens of economic benefit.

Recognition that as human beings we are interdependent creates a positive value to the quality of care we afford the other human person (Gade, 2012). The contribution of people with ID in creating harmonious societies around the world continues to receive recognition as an important role (Woodcock, 2009; Berghs, Dos & Zingale, 2011; Boelsma, Caubo-Damen, Schippers, Dane & Abma, 2017). The understanding that human beings rely on each other calls for a different conceptualisation of dependence as a human characteristic (Tronto et al., 2006). Such a conceptualisation can help people with ID to access justice and dignity through caring relationships without feeling guilty of being dependent or their worth of being existent being debated.

Experiences from communities that have been intervening with supports for people with ID such as L'Arche can help to understand the role of an ethics of care in the wellbeing of people with ID and the benefits of mutuality of caring relationships. Jean Vanier, the founder of L'Arche communities, addressed the issue during his speech at House of Lords on the topic "How the weak help the strong". He first explained pain and aggression commonly seen as the presence of problematic behaviour in people with ID as a manifestation of psychological pain caused by rejection, humiliation and ridicule which denies people their sense of human worth and dignity. Speaking from 50 years of experience living with intellectually disabled people, Vanier notes

that authentic relationships through real encounters between caregivers and people with ID liberate individuals from such inner pain. Acceptance and affirmation conveys to the individual's self-worth a sense of belonging and slowly dissipates fear. The transformation allows people to manifest their human values of tenderness, love, care, openness and compassion. Vanier describes belonging as a yearning of every human being because of our interdependence, without which people suffer terrible loneliness. Relationships and encounters of interdependence are therefore seen to bring value in society beyond the caring relationship but help in breaking down prejudices and accepting difference to create peace. Such encounters are mutually enriching since they not only liberate the disabled member but also reveal to people who share their lives with the disabled members their own fragilities in emotional, psychological and spiritual aspects. The discovery that we have different challenges and limitations has the potential to stir people towards self-liberation (Vanier, 2015). Lindemann (2009) calls it "holding one in personhood", which is an act of helping people retain their humane identities. On this basis, ethics of care is a strength for families who see it as mutually benefitting and developing a character of resilience and restored humanity (Carlson & Kittay, 2009; Bekhet, Johnson & Zauszniewski, 2012).

2.4.1 Similarity of ethics of care and ubuntu

From an African perspective, ethics of care can be likened to the African ethic of *ubuntu* in that they are both relational approaches that recognise the interdependence of human beings. *Ubuntu* in Africa has been viewed as a moral quality that shapes attitudes and values that manifest in the way people relate with each other. Relationships among people stem from the belief that human beings are interconnected and are interdependent on each other which is what makes them human. Community is therefore the reference through which personhood is defined (Nussbaum, 2003; Murithi, 2006; Bidwell, 2010;). Values of generosity, hospitality, friendship, reciprocity and care are nurtured to bring about dignity and harmony (Nussbaum, 2003; Bidwell, 2010; Gade, 2012). Rossouw and Naude (2007) argue that these non-economic components of quality of life are the fundamental foundations in building a morally responsive society.

Swanson (2007) views *Ubuntu* as a possibility to contribute towards realising individual human rights by affirming dignity of all. It does not stop at dignity just being a right of an individual but operationalises values of oneness or unity of a society through relationships. From the perspective of how attitudes shape our thoughts and actions, the ethics of care and *ubuntu* debates seem to be of importance when discussing quality of life and supports for families of

people with ID. They both form ontological and epistemological perspectives of how cultural beliefs and norms shape societal attitudes. The positive ethics of care and *ubuntu*, if applied in the same way to perspectives on disability, can be a strength while seeking for justice and dignity that people with ID and their families seek.

Values of *ubuntu* and ethics of care challenge communities to move beyond the fear of difference so as to act justly. In the spirit of oneness and regard for fundamental human dignity, society can provide supports necessary to enhance livelihoods for individuals with ID and value them for the important contribution they can make in society in their own unique way (Woodcock, 2009). This hurdle that has to be overcome is in the manner in which neoglobalisation challenges the spirit behind *ubuntu* and ethics of care by fostering individualism above all else (Grech, 2011). Apart from denying opportunities of transformation that care relationships foster, it also disenfranchises people with ID who cannot compete on a level ground with other members in society if denied supports.

2.5 Conceptualizing Quality of Life in the field of intellectual disability

According to Verdugo, Schalock, Keith, & Stancliffe (2005), Quality of life is a multidimensional construct which has been referred to as happiness, wellbeing, flourishing and excellence, all of which are perspectives that have been used to infer satisfaction with the individual's circumstances (Schalock et al., 2002; Hughes, 2006). The diversity in what quality of life represents to different individuals is driven by culture, environmental difference and lived experience, which produce meaning (Schalock et al., 2007). Brown (2017) argues that, although perspectives about wellbeing are perceived subjectively and given meaning by an individual, they are rendered objective if the meaning and perception are shared by individuals in the same circumstances. The common discussions of objective quality of life domains for people with ID in the literature comprise of emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and rights (Schalock, 1993; Lachapelle et al., 2005; Summers et al., 2005; Verdugo et al., 2005; Wang & Brown, 2009). Additionally, respect, integration and recognition of human rights are some of the lenses through which people with ID perceive their quality of life (Wang & Brown, 2009; IASSIDD, 2013; Vanier, 2015). Different circumstances impact on individuals with ID and their family members in unique ways and require a deeper understanding of their quality of life to establish their support needs.

2.5.1 Family Quality of Life (FQOL) paradigms in the field of intellectual disability

Family quality of life (FQOL) has developed as a concept in the field of ID in recognition of the role families play in the lives of people with ID, as asserted in a number of studies (Bertelli & Brown, 2006; Wang & Brown, 2009; Claes, Van Hove, Vandevelde, Van Loon, & Schalock, 2012; Brown, 2017). In the context of this study, family quality of life is a peek through the factors such as emotional, physical, spiritual, economic, social, political and so on that influence the operation of families of people with ID. It has been argued that the family is the immediate natural environment an individual with ID lives in and mostly relies on for supports (Turnbull & Turnbull, 2002; Wang & Brown, 2009). The proximity of the individual with ID to family members means that the family understands the needs of the individual, notices changes and makes adaptations where necessary (Wang & Brown, 2009; Schertz, Karni-Visel, Tamir, Genizi, & Roth, 2016). Family members have a constant influence on development and shaping of life experiences for the member with ID across the lifespan. They nurture helpful and congenial relationships which catalyse social integration and increase autonomy (Dempsey & Keen, 2008; Wang & Brown, 2009; IASSIDD, 2013; Asselt-Goverts, Embregts & Hendriks, 2015).

What this means is that families have a huge responsibility towards support and ensuring progress for their members with ID. Different dynamics occur in the family owing to this responsibility that necessitates supports for families and the disabled members if support strategies are to be successful. Some of these dynamics include balancing care needs of the disabled member and personal needs of the caregiver, the psychological wellbeing of family members and currently debates around dynamics of inclusion and exclusion of family members versus people with ID are gaining importance (IASSIDD, 2013; Boelsma et al., 2017; Brown, 2017). Success with support services and strategies requires careful consideration of the realities families are facing and collaborative services that support families (IASSIDD, 2013). Isaacs et al. (2007) note the importance of taking cognisance of the role of families in supporting their members with ID and the impact this has on the family quality of life so as to provide supports for effective implementation of this role. In the preamble(X) of the United Nations Convention on the Rights of Persons with Disability (UNCRPD), the role of families in contributing to full and equal enjoyment of disability rights to their members is recognised. It is therefore important for State parties that have ratified the convention to offer protection and assistance to families for effective fulfilment of support roles (UNCRPD, 2006).

2.6 FQOL measurement tools

Family Quality of Life is proposed as a paradigm for research, policy and interventions in the field of ID (Dempsey & Keen, 2008; Zuna et al., 2010; Brown, 2017). A number of tools have been developed to understand the family quality of life and the impact on the family wellbeing across cultures.

The two commonly used tools for measuring family quality of life for families with intellectually disabled persons include Family Quality of Life Scale (FQOLS-2006) which has quantitative measures and the Beach Centre FQOL scale which also has quantitative measures and a similar version (the Beach Centre FQOL conversation guide) which collects qualitative data. The tools are geared towards informing and evaluating individual and family outcome measures to inform policies and supports at individual, family, societal and national levels.

The FQOLS-2006 was developed from three contexts (Canada, Australia and Israel). It measures importance, opportunities, initiative, stability, attainment and satisfaction in the domains of health, financial wellbeing, family relationships, support from other people, support from services, careers and preparing for careers, spiritual and cultural life, leisure, and community and civic involvement (Brown, Anand, Fung, Isaacs, & Baum, 2003; Isaacs et al., 2007). The tool is more quantitative in nature and can therefore limit perspectives of FQOL that have not been generated from its context. Participants respond only with the different measures to the FQOL domains without providing their meanings or how they perceive these domains. It also has a wide range of measures that makes it complex to use with people who have ID.

The Beach Centre FQOL Conversation Guide, however, allows participants to share their subjective opinions of FQOL. It describes importance of, satisfaction with and priority of support in the domains of family interaction, parenting, emotional wellbeing, physical/material wellbeing and disability-related supports (Poston et al., 2003; Park et al., 2003; Summers et al., 2005; Hoffmann et al., 2006). This makes the Beach Centre FQOL Conversation Guide the most favourable tool for this study because it offers participants an opportunity to speak broadly about the different perspectives of FQOL through their own lived experiences. Further, the three descriptions (importance of, satisfaction with and priority of support) are easier for participants to understand and to guide conversations with participants, especially because of the involvement of people with ID in the study.

2.7 The challenge of research in FQOL for people with intellectual disability in Africa

Consistent with findings of WHO Atlas ID, few studies regarding FQOL have been carried out in Africa. In an African context, FQOL would be valuable to establish the required services and form the basis to measure outcomes of the services. Conceptualisation of FQOL in Africa seems to be consistent with global findings. A study conducted in Nigeria using the FQOLS-2006 showed that family relationships, values and health contributed to FQOL, while a lack of supports detracted from it (Ajuwon & Brown, 2012). Owing to the quantitative nature of FQOLS-2006, this study did not generate specific Nigerian cultural perspectives of FQOL for individuals with ID.

Another study conducted in the Democratic Republic of Congo (DRC) found the FQOL domains of the Beach Centre FQOL scale to be relevant there. The study also revealed the influence of poverty and resilience on FQOL in DRC (Aldersey et al., 2017). The relevance of the Beach Centre FQOL in the African context, its consistency with global conceptualisations of FQOL, and the possibility of bringing out participants' own perspectives informed the choice of the tool for this Kenyan study.

In Kenya, there is no data, legislation, policies or guidelines on issues affecting people with ID and their families. Family support is therefore not known. The only service provided by government is cash transfers to people with disability, although these are inconsistent due to a lack of reliable statistics on the number of people with disability. Similarly, the FQOL for individuals with ID and the nature of support systems they require is unknown. This study is an attempt to establish the FQOL for people with ID in Kenya. The dynamics of culture, daily practices, engagements and interaction within and outside the family will be explored to find out how these factors influence the quality of life. It is my hope that findings of this study can be a step towards informing supports for families and service providers, and further, that the findings of this study can enhance legislation, guidelines and policies for people with ID and their families in Kenya.

3 CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter is a description of all the processes I engaged in, in this research study. Shenton (2004) argues that it is important to provide details about the research process to ensure that it can be replicated to generate similar results, which helps to increase the credibility and trustworthiness of results. In light of this, I have provided a detailed description of the research process: the choice of the design and the rationale behind it, the sampling process, the research setting, ethical considerations, and data collection, including the instrument used and the process. I have also provided my background information which is useful to understand as this is a qualitative study and my interaction with the data could be influenced by my perspectives. I end the chapter by explaining the process I undertook to analyse the data and write it up.

3.2 Research design

I chose a qualitative paradigm as the most appropriate one for this study because the objectives of this study were to explore the perceptions of FQOL and support needs of individuals with ID and their caregivers. There is an African proverb that says, "The one who sits at the bottom of a tree is the only one who can tell what black ants feed on". This is because black ants inhabit trees at the bottom of the trunk and there you can watch them and see what they feed on. It therefore goes without saying that it would be difficult to speak about an issue of concern if you did not experience or understand it. Qualitative research explores the variety of perspectives people have about the issue under study. The meanings of the experiences and the beliefs embedded are revealed based on how people interpret their experiences. It therefore enhances the understanding of the phenomenon under study (Creswell, 2014; Parahoo, 2014).

Therefore, the choice of a qualitative design was informed by understanding that people with ID and their caregivers would be best to tell their perspectives of their FQOL and support needs according to the interpretations they made of their daily experiences. The voices of people with ID are hardly heard in the Kenyan context and the few interventions (if any) to their plight are based on opinions from proxies. There's a general misconception that people with ID cannot represent themselves which has left them marginalised and misunderstood for a long time, with services for them barely existing in Kenya. It was also important to listen to caregiver's

perspectives to give a holistic understanding of dynamics in a family which has a member with ID. I used the Beach Centre FQOL Conversation Guide to collect views from caregivers (see Appendix 1) and a simplified version of the same for people with ID (see Appendix 2).

3.2.1 Transformative emancipatory approach

This study incorporates a transformative emancipatory approach to its methods. Transformative emancipatory research has been used by marginalised populations that want to advocate for social justice and the need to have recognition of their human rights (Munger & Merten, 2011). It involves the active participation of the researched group in the whole cycle of the research process (Kachaje et al., 2014). The approach is concerned with ethical processes of the study, how knowledge is co-created with the group under study, and an exploration of the knowledge discourse of how beliefs and attitudes shape the way they experience their phenomenon (enhancing or deprivation of social justice). The need to create knowledge with the group advocating change is a key characteristic of this approach.

3.2.2 Identifying the research assistants

While conducting research with marginalised populations seeking social justice, emancipation of the research population has been advocated to dissolve power relations, to empower the research population and for the study population to own the research process and findings, therefore giving them the strength to advocate their agenda (Carlson, 2013; Coons & Watson, 2013). In line with the transformative emancipatory approach, I looked for two individuals with ID to work with me as research assistants for data collection of people with ID. I had a friendship and working relationship with them, having lived with them for eight years in the L'Arche community in Nyahururu. To bring them on board into conducting research, I trained them on the activities they would be involved in as explained in the next section. I considered their ability to understand Kikuyu and Kiswahili well as they were effective communicators, a skill they possessed even before this research study. I also had confidence in their ability to maintain confidentiality. Both of them were involved in all interviews of individuals with ID and focus group discussions. Additionally, I requested a parent of a child with multiple impairments to be my research assistant in interviewing caregivers and the focus group discussions. The parent had a good command of English, Kiswahili and Kikuyu. She was a young parent and was passionate about advocating for people with disability in the local community. Parents liked her and were

confident that she represented their concerns well in any forum they sent her. With this confidence, I decided to ask her for support in the research process which she consented to. They therefore were involved in the knowledge created in this study and for the first time were involved directly in conducting research. They helped with data collection and member checks between January and March 2017.

The research assistants received Ksh 100 for every hour they worked with me. I also reimbursed the research assistants and participants for transport when they travelled for purposes of the study. After the focus group discussions (FGDs), refreshments were served.

Going the emancipatory way has the advantage of members of the group being researched gaining knowledge and experience of the research process and confirming that their needs are adequately being met by the study, which adds credibility to the study (Munger & Merten, 2011). However, I had limitations in implementing the ideal transformative emancipatory approach in the sense that participation was not possible in all research processes. For example, as the study was being conducted in Kenya and I was a masters student in Cape Town, it was impossible to involve participants when I was developing the proposal and later during analysis and writing up the discussion, which required me to be in Cape Town. It also is a time consuming and expensive venture. However, on completion of writing, I returned to Kenya and had discussions with the research assistants and updated them on all the findings and conclusions I had drawn from the study in September 2017. We also gave feedback to all participants in the study regarding their perspectives of FQOL and support needs in October 2017. Each participant was given an easy-to-read report of the research which I did myself and translated into Swahili.

3.2.3 Training the Research assistants

Caregiver

Training of the research assistants took place in December 2016. I trained the parent separately as she understood things at a different pace to the two research assistants with mild ID. Training included an introduction to the study and its purpose. I clarified that we were to ask participants about their FQOL and that we would record participants' responses without trying to influence their perspectives. I introduced the Beach Centre FQOL Conversation Guide, which was to guide

our interviews, one afternoon for two hours to the parent (see Appendix 1). When she understood what all the 25 questions were asking, I explained to her that our role was to ask and give ample time to parents/caregivers to answer, to probe further and to record the data. I also explained to her that it was important for us to capture the importance participants placed on each section (domains), their satisfaction with the current situation in the domain, and the priorities for supports, which were the goals of the study.

People with intellectual disability

I also met with the research assistants with ID every afternoon for about an hour for two weeks to train them on how to conduct research with me. First, I explained the study to them, the goal and the objectives. We then looked at the Beach Centre FQOL Conversation Guide which I explained was going to help us collect information from participants (see Appendix 2). I ensured that they understood that participants were going to discuss with us all the questions they were comfortable answering in the interview guide. In addition, they would tell us how important the issue was for them, how satisfied they were with their current situation around the issue, and the priority they would suggest for support. I introduced to them the three pictures we would present to participants to rate their priorities as high, medium or low. These pictures were three emoticons which had a happy face, a neutral face and a sad face. The research assistants understood that we were to help the participants understand the meaning of these faces so that they could use them effectively. On the last day of training, they practiced asking questions to their colleagues with ID by way of a game where they could ask a random question that necessitated one to rate importance or satisfaction. To answer, one needed to select a sad, neutral or happy face that best described their rating of importance or satisfaction of the question asked. The research assistants would be asking one question at a time and waiting for the responses from the participants as I recorded the conversation. I would probe further when I felt there was need for further clarification. At the end of each set of questions in each domain of the Beach Centre FQOL Conversation Guide, the research assistants would present the three emoticons (sad, neutral, happy) to participants to rate the importance, satisfaction and priority of support for the FQOL domain being discussed.

3.2.4 Researcher's positionality

Given that this is a qualitative study, my own perspectives and assumptions are inherently embedded in the way I conducted the study and interpreted the results. It is therefore important to have a background understanding of myself as one of the research tools involved in this study. To begin with, my contemplating this study as the researcher was informed by 15 years working as a physiotherapist with disabled children, their families and the community in rural Kenya. During this period, I lived for 8 years in a L'Arche community in Nyahururu with people with ID supporting them with daily activities. I had an extensive experience of friendship and working closely with people who have ID. As a native, I understood cultural perspectives of the Kenyan people towards disability, have interacted with families while listening to and observing their experiences of having a member with disability in the household, and have practical experience of supporting members with ID. This experience helped me engage with people with ID and caregivers as participants and also as research assistants during the research process. From experience, I felt strongly that people with ID could advocate for themselves, hence their involvement as research assistants and conducting individual interviews. It is my opinion that this would greatly add value to the data collected as representative of true perspectives of life experiences for people with ID. I used my experience in living and working with people with ID to ask questions in a way that they understood, giving them the opportunity to make choices and respecting their opinions. My having a relationship with individuals with ID helped in the way they relaxed during interviews and the freedom they would have, such as asking for a break. Due to my extensive experience working in the community, the plight of families of people with ID was not foreign to me. Even in the initiatives of the programme for people with disabilities that I worked in, there seemed not to be practical solutions to interventions for people with ID. There were no interventions that considered families, although there was evidence that families experienced challenges too. I therefore decided to conduct this study on these premises hoping that the process would also be empowering for families.

3.3 Research setting

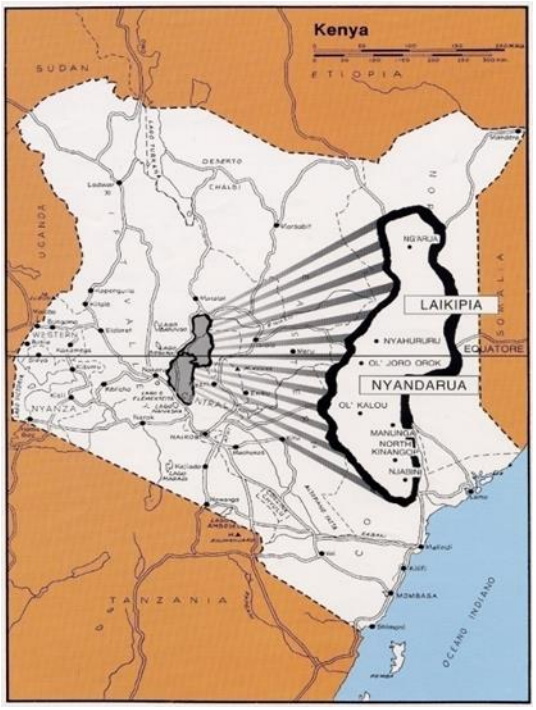


Figure 1: Map of Kenya showing research setting

The study was conducted in Nyahururu, Kinamba and Ol'ngarua in Laikipia County in Kenya, which is predominantly a rural setting. The three areas are approximately 50 km apart from each other and are inhabited by people from Kikuyu, Kalenjin, Samburu, Turkana, Maasai and several other ethnic communities, which gives it cultural diversity. According to the Kenyan National Bureau of Statistics report of 2009, the population in Laikipia stood at 399,227. Some communities are pastoral and therefore adopt a nomadic lifestyle, while others are agricultural communities with different cultural practices depending on ethnicity. Most residents communicate in their mother tongue in non-formal settings but use English and Swahili as official languages, with Swahili being the most commonly spoken and well understood language among the residents. The population living below the poverty line in Laikipia County as at 2012 stood at 43%, which means approximately 171,667 people were living on less than 1 US Dollar per day. The main economic activities are subsistence farming and small businesses. Many people depend on casual labour in the farms (Laikipia County Assembly Report, 2014).

3.4 Data collection instrument

3.4.1 The Beach Centre Family Quality of Life Conversation Guide

We used the Beach Centre FQOL Conversation Guide to conduct structured interviews. The Beach Centre FQOL Conversation Guide measures satisfaction in the domains of family interaction, parenting, emotional wellbeing, physical/material wellbeing and disability-related supports. The conversation guide (Appendix 1) has a total of 25 questions – 7 under family interaction, 5 under parenting, 5 under physical/material wellbeing, 4 under emotional wellbeing and 4 under disability-related supports (Poston et al., 2003; Park et al., 2003; Hoffmann et al., 2006). The ideas and questions captured in the conversation guide are summarised in Table 1 below.

Table 1: Summary of Beach Centre Family Quality of Life Conversation Guide

Theme	Ideas capture	Questions
Family interaction	Dynamics of life as experienced by family members. How different situations impact on family members.	Questions were on the quality of time spent together with family members, communication, happiness, expressions of love and care, communal family activities and support, family strategies in solving problems and difficulties.
Parenting	The parenting experience of having a young adult with ID, success and challenges of the parenting and advocacy	Questions were on how parents supported individuals with ID in activities, decision making, and socialising, and how they managed care for all family members
Physical/Material Wellbeing	Physical, health and material wellbeing of the family members	Questions were on experiences with transport, safety at home and in the community, and availability of medical and dental care
Emotional supports	Emotional wellbeing of family members and factors that facilitate it.	Questions were on availability of professional psychosocial support, social support, respite and other support.
Disability-related supports	Holistic support strategies for people with ID	Questions related to support that people with ID receive at home, work and school, and social networks for people with ID and relationships with service providers.

I chose this tool because it has been used in several other studies from different contexts globally to measure FQOL for individuals with ID and was found to be relevant even in the African context (Summers et al., 2005; Hoffman et al., 2006; Davis & Gavidia-Payne, 2009; Meral,

Cavkaytar, Turnbull & Wang, 2013; Aldersey et al., 2017). My choice was also based on the ability of the tool to collect qualitative data in a uniform manner using the same set of questions to enable similar assessments of FQOL. This interview guide was also easier for people with ID to understand as it had only five domains and required rating three responses, namely importance of, satisfaction with and priority of support. It was a much easier way to help participants with ID to describe their situation.

For example, to determine the importance of any domain the participants would describe it as high. When it was low, it meant that it was not an important FQOL domain. When priority for supports were described as high, analysis and conclusions regarding supports were drawn from them. If satisfaction with a FQOL domain was low, it helped further the discussion during interviews on how things needed to be improved and were discussed in the analysis and discussion. If satisfaction was high, it meant that participants were okay with the FQOL domain area and did not require further supports in it. Participants would then explain their responses during interviews. The interview guide also created the opportunity for participants to provide other relevant information emanating from their experiences which would inform individual and FQOL from contextual and cultural perspectives. Outcomes of this study would therefore position the situation of FQOL of individuals with ID from Kenya in the global context.

3.4.2 Piloting the study

Since the Beach Centre FQOL Conversation Guide had not been used before in Kenya, I conducted a pilot study to find out if participants related to the FQOL domains in the questionnaire and to make adjustments if the questions were not well understood. We conducted a pilot with two people with ID and two caregivers from Nyahururu. I chose to do the pilots in Nyahururu because it was convenient for us as I and the research assistants who I engaged in the study lived in Nyahururu.

Caregivers were able to understand the questions sufficiently. However, they consistently alluded to the fact that receiving dental care was addressed by the question regarding receiving medical care and so the question about receiving dental care was removed.

We also piloted the Beach FQOL Conversation Guide so that we could adapt it for the convenience of individuals with ID. The parenting section and accompanying questions were removed since none of the participants with ID in the pilot and those selected for the main study

had a family or were parents themselves. The questions presented to individuals with ID were also changed to be closed-ended questions which necessitated a Yes or No response followed by an inquiry into their response (see Appendix 2).

We also wanted to establish the importance of the FQOL domains in the Beach Centre FQOL Conversation Guide from our participants' perspectives and so we included measures of importance of, satisfaction with and priority of support for each domain. Participants gave a rating of high, medium or low for these measures. We gave three emoticons to participants with ID which they could associate to the rating they felt best described their perception or experience. A sad face meant a low rating, a neutral face meant a medium rating and a happy face meant a high rating (see Appendix 2)

3.5 Data collection

3.5.1 Recruitment of Research Participants

The participants came from three different locations (Nyahururu, Kinamba and Ol'ngarua) and had different ethnic backgrounds (Kikuyu, Kalenjin and Samburu). These factors were deemed sufficient to sample a range of differences in FQOL that would arise from geographical differences, occupation and culture. It is important to mention that although the sample included parents/caregivers and people with ID, the intention of the study was not to directly compare perceptions of quality of life and support needs among them but to understand the current situation, taking into account the different perspectives of the participants' groups.

The participants were identified through head teachers of special schools in Nyahururu and Ol'ngarua and a village elder in Kinamba. The head teachers and village elder identified all potential participants within their jurisdiction (parents of people with ID as well as individuals with ID). These were people who were receiving services intended for people with ID, identified through educational assessment or diagnosis given by a hospital. Five people with mild ID and six caregivers volunteered to participate in this study. People with ID were considered to have mild impairment if they were able to receive and return communication as well as participate in activities of daily living such as bathing. The ability to carry out some chores at home or school such as cleaning up with minimal assistance was also considered part of a mild impairment.

3.5.2 Sampling

Only individuals with ID who were 18 years old and above were sampled. I was given telephone contacts of 10 parents of people with ID from each zone. I called them to a meeting in their respective zones, together with their family members with ID, to explain the study and ask for volunteers to participate. I set the date, time and venue of the initial meeting close to their locations. The majority of the parents managed to attend with seven in Kinamba, ten in Nyahururu and six in Ol'ngarua. They each attended with their disabled family member. I explained the study to them using Kikuyu and Swahili languages and gave them time to ask questions where they needed clarification. The parents assisted me to help the individuals with ID understand when needed, although, for most of the part, I observed that we understood each other well. The language I used was very basic and as a person who lives in the same area and grew up using the same language, it was easy for me to connect with the participants.

3.5.3 Inclusion Criteria

People with intellectual disability

- People who received services aimed for people with ID who were above 18 years.
- Participants who could understand Swahili which was the common local language understood by the researchers.
- People with ID who had a way of articulating their needs verbally or by way of augmented communication understood by the researchers.
- Written consent from a parent/guardian for participants with ID (see Appendix 3).

Caregivers

- A family member or caregiver who was a legally authorised guardian of a person with ID.
- The parent or caregiver had to be responsible for care of the individual with ID for at least 6 hours daily to be able to understand the needs of the intellectually disabled person better and their own support needs based on experience.

3.5.4 Exclusion criteria

- Family members whose member with ID has been included in the study to avoid the intellectually disabled member from feeling intimidated or unable to open up fully for purposes of the study.

In each of the zones, I asked for volunteers and almost all participants wanted to participate as they felt it was an opportunity for them to speak about a subject they had never been asked about before. We therefore decided to conduct random sampling from the group of willing volunteers. The parents/caregivers were separated from individuals with ID in each zone (Nyahururu, Kinamba and Ol'ngarua). We wrote the desired number of 'yes' responses for each zone and many 'no' responses on small pieces of paper and folded them. Participants from each category picked one paper. The participants with the 'yes' response were included in the study. In total, fifteen participants participated in the study.

3.5.5 Informed Consent and Ethical Considerations

All participants received an information sheet that had details of all aspects of the research process, i.e. the aim of research, why we selected them as participants, time the interviews would take, the right to withdraw from the study at any point during the process, details about psychological support the participants would get should they experience psychological or emotional problems during the process, benefits of the research, details of ethics approval, my contact details and those of the ethics committee, and a disclaimer that participants would not be receiving remuneration for participating in the study for caregivers (Appendix 4) and people with ID (Appendix 5). For participants with ID, this was presented as short sentences in simplified Swahili language and I also read it out to them individually to ensure they understood its contents. The guardians of the participants with ID were also given the information sheet.

Attached to the information sheet was a consent form in Swahili which participants signed only when they confirmed to me that they had understood the study and were willing to participate without coercion (Appendix 5). We agreed on the appropriate venue for our next meeting with each participant and ensured that it provided privacy and comfort to the participant. All participants chose the convenience of their homes as, particularly for individuals with ID, familiarity seemed to matter as well as less distraction.

We received the signed written consent from all participants who were included in the study and from parents/caregivers of participants with ID. Participants with ID who were unable to sign wrote their names or put thumbprints which was a contextually acceptable practise for people with ID. Verbal consent was also received continuously throughout the study by checking with the participants if they were okay with the proceedings of the interviews. This was especially

helpful for individuals with ID who understood the research process as it unfolded and therefore it was necessary to keep checking that they were comfortable and were assenting to it (Munhall, 1989).

Ethical approval was granted by the Human Research Ethics Committee (HREC) at the university of Cape Town (HREC number 616/2016: See Appendix 6). A research permit to conduct research in Kenya was granted by the National Commission on Science, Technology and Innovation (NACOSTI) in Kenya (permit number NACOSTI/P/17/66720/14996) (See Appendix 7). Tables 2 and 3 below show the demographic characteristics of participants. CG denotes caregivers and PWID denotes people with ID.

Table 2: Characteristics of Participants with intellectual disability

Participant ID	**Age**	**Gender**	**people living in house**	**Occupation**	**Location**	**Focus group discussion**
PWID 1	20	Female	6	School	Nyahururu	FGD1
PWID2	28	Male	6	Sheltered workshop	Nyahururu	FGD1
PWID3	25	Female	2	None	Kinamba	FGD2
PWID4	26	Male	3	Grazing	Kinamba	FGD2
PWID5	18	Male	6	None	Nyahururu	FGD1
PWID6	25	Female	10	Casual Worker	Ol'ngarua	FGD2
PWID7	20	Male	4	School	Ol'ngarua	FGD2

Table 3: Characteristics of Caregivers

Participant ID	Age	Gender	People living in house	Age & Gender of PWID(s)	Nature of impairment of PWD(s)	Occupation	Location	Focus group discussion
CG1	39	Female	3	18 Female	Profound multiple impairments	Casual worker	Kinamba	FGD2

CG2	35	Female	6	21 Male	Mild ID	Casual worker	Nyahururu	FGD1
CG3	63	Female	4	30 Male 45 Female	2 mild PWIDs	Small business	Nyahururu	FGD1
CG4	70	Male	7	23 Female	Profound multiple impairments	Farming	Kinamba	FGD2
CG5	35	Female	6	18 Female	Severe Cerebral Palsy & ID	Farming	Ol'ngarua	FGD2
CG6	37	Female	5	20 Male	Profound multiple impairments	Small business	Ol'ngarua	FGD2
CG7	45	Female	5	26 Male	Mild ID	Small business	Nyahururu	FGD1
CG8	32	Female	4	30 Female	Down Syndrome	Casual worker	Nyahururu	FGD1

People with mild ID included in the study as participants ranged between 18 and 28 years of age. Some of the people with ID supported by caregivers were above 30 years of age as indicated in Table 3 above. Two of them did not have any occupation and remained home all day, two were still going to school, one was in a sheltered workshop and two had a daily occupation (grazing and casual work). Among the eight caregivers, seven were female and one male. This was mostly attributed to care responsibility in the region being mostly vested in mothers as well as single parents. All of them depended on casual work on the farms, although two owned small pieces of land and three others supplemented the casual work with small businesses that they ran in the evenings.

3.5.6 Interview Content

We conducted two interviews for each participant. In the first interview, we were collecting perspectives of participants about what in general was a good life to them. This was to aid us in

the understanding of what a good quality of life meant for them. In the second interview, we were finding out participants' perspectives of FQOL in the scope covered by the Beach Centre FQOL Conversation Guide. It was possible to receive further opinions not covered in the interview guide from participants as additional comments were allowed at the end of the interview.

3.5.7 Familiarisation Process

Conducting research with participants with ID was a new experience to us all. I therefore organised a familiarisation process so that they could get to know the research assistants and myself and introduce them to the tools that we would use during interviews. We made appointments with participants with ID at home and consulted with their caregivers. During the agreed time, we met participants at home and ensured they were comfortable and that the venues provided enough privacy for them. We introduced ourselves and explained that we were going to ask the questions on the Beach Centre FQOL Conversation Guide (Appendix 2). We clarified to participants that they were at liberty not to answer questions they didn't feel okay answering. We then explained that we would record the interviews and that I would be taking important notes in a notebook as the interview progressed. I showed the notebook and the Samsung phone we used for recording. The research assistants showed the questionnaire we were going to use with the three emoticons. They explained the meaning of each emoticon and played a game to illustrate how the participant would use the sad, neutral and happy faces. They asked us random questions of things that were important to us and we were asked to pick the face that depicted what we felt. They asked us how satisfied we were and we took turns picking the face that most described our answer. This exercise took approximately one hour with each participant, and we conducted it with each person over a period of one week. When all participants were comfortable with the process, we asked each of them to attend two individual interview sessions on separate days.

3.5.8 Collection and Recording of Data

During the first interview, we took the demographic information and asked the general question of what a good life meant from the participant's perspective. I recorded and took notes during this interview, while my research assistants asked the questioned. The presence of research assistants may have contributed to participants with ID understanding research questions due to use of simple local language, feeling at ease and opening up in their responses. The research

assistants assisted with ensuring that the participants with ID were comfortable with the questions and that they understood them. For example, when participants with ID deviated from answering the interview questions, the research assistants helped them to focus back to it by reminding them what the question was and probing them. I also would ask for further clarification whenever I deemed it necessary. They also gave participants sufficient time to answer. For example, after every 15 minutes, the research assistants asked if participants with ID needed a break. They could help them take a walk and come back to continue the interview. These interviews took 20 to 30 minutes per participant. It took us two weeks to collect this data. All interviews were recorded on a Samsung smartphone device and saved in a folder in my laptop named Project 1. Each interview was given a unique identification code with initials of the participant's name and a number in the sequence that we conducted the interviews. I also saved a Word document with the demographic information using the same identification code as the participant's audio recording.

The second interviews were on the FQOL using the adapted Beach Centre FQOL Conversation Guide (Appendix 2). The research assistants asked the questions while I recorded and took notes. We also used probe questions when we felt participants had not given enough information. These interviews took approximately 45 minutes per participant. We conducted them over a period of three weeks. In this second interview, one individual with ID asked us to break the interview into two days for 20 minutes each for his convenience which we did. I saved the recordings after each interview on my laptop in the Project 1 folder in another folder called Interview 2. Each interview was saved using the unique code name similar to the first recording for identification.

3.6 Data analysis

3.6.1 Transcription

When all interviews had been done, I transcribed the recordings verbatim in Swahili and Kikuyu. It took me two weeks to complete transcribing and it helped me to familiarise myself with the data. I read through the transcripts, listening to the corresponding recording to confirm there were no alterations or missing data. I translated the transcripts into English since I understood the languages very well and I had the advantage of having been present during the interviews. I gave both the Swahili/Kikuyu and English versions to a language expert (Swahili/ English high school teacher whose native language was Kikuyu) from the region. The language expert verified that

the original and translated transcripts were similar in text and cultural meaning. I then collated the demographic information, interview 1 and interview 2 for each participant into a Word document and saved them under Project 1 folder on my laptop under a new folder called Transcriptions and labelled them Transcript 1 to 15. I used the previous unique identification code from the recordings in place of the name in the demographic information.

3.6.2 Data Confirmation with Participants

To confirm the data with my research assistants and participants, I organised for two FGDs in Nyahururu and in Kinamba. Participants from Ol'ngarua travelled to Kinamba and I provided for their transport. I chose convenient venues where participants could sit comfortably and interact freely without interference or disturbance. I requested them to sign a confidentiality agreement form (Appendix 8) for the exercise. I collated information from interview 1 and interview 2 and presented it in to the participants in FGDs to confirm accuracy and validity of the data. The parent co-researcher was recording and taking notes in the FGDs. Participants in all three zones confirmed the accuracy and validity of the data and added more information that they felt they had not provided during interviews. I took note of the fact that when caregivers and people with ID spoke about their issues together, they were able to strengthen each other's concerns and the idea of meeting to share and support each other grew. The FGDs took about 2 hours as participants felt it was a therapeutic process, speaking and listening to each other about something they had in common. I later typed the FGD notes and saved them under a folder named Focus Group Discussions in the Project 1 folder on my laptop. I also transcribed the FGD recordings verbatim and saved them as FGD Kinamba, Nyahururu and Ol'ngarua respectively so that I could add the new information to the data.

3.6.3 Thematic Analysis

I chose to do a thematic analysis which is a method of identifying, analysing and reporting patterns in data. Thematic analysis involves transcribing data, reading and familiarising oneself with the data, generating codes from a list of ideas with similar meanings, collating the codes that have similar meanings into themes, reviewing the themes, and producing a report (Braun & Clarke, 2006). I read and re-read the transcripts to understand the data. Transcribing the data personally also helped me internalise the information in the data more. I applied a deductive and inductive analysis to the data.

Deductive Analysis

As I read through the transcripts, I identified and highlighted the data that corresponded in meaning to the domains of the Beach Centre FQOL Conversation Guide (family interaction, parenting, physical/material wellbeing, emotional wellbeing and disability-related supports) which I used as the themes. This data formed the basis of a deductive analysis of perspectives on FQOL of participants in Kenya. All responses to the questions asked under these themes were collated together under the themes. Additionally, each theme had several questions whose responses were collated together with the main idea of the question serving as the sub-theme.

Inductive Analysis

Within the existing themes of FQOL, people with ID and caregivers sometimes gave different factors that influenced a specific theme. I used these as the sub-themes that best explained the theme. For example, under the family interaction theme, some new sub-themes included receiving equal treatment in the family, involvement of people with ID in the family, and interreliance of the family for support. The theme of parenting had additional factors influencing it, such as challenges in providing basic necessities, parental advocacy, spousal support, concern for lifelong support, providing personalised care to people with ID and cultural dilemmas linked to parenting people with ID. A new theme of community supports was created due to frequent attribution to it from the raw data. The sub-themes that added meaning to it included cultural beliefs and practices and mutuality of support by the community.

3.6.4 Using Dedoose to Analyse the Data

I used Dedoose software version 7.5.15 which is used for qualitative research or mixed methods for analysis. I chose Dedoose because it was possible to have visual representations of patterns in the data in terms of participant characteristics which were termed as descriptors. I entered the demographic information as descriptors in Dedoose which included the participant's ID, gender, age, location, guardian, number of households and daily occupation. To differentiate data of people with ID from caregivers, I used the initials PWID to denote people with ID and CG to denote caregivers which I entered as dynamic descriptors. The dynamic descriptor field allowed me to separate data received from individuals with ID and caregivers. It was easy at a glance to view these differences on a computer screen rather than doing it manually. It provided ease in drawing associations between demographic factors and data from people with ID as well as caregivers separately.

Coding Themes

After creating the descriptors, I uploaded each transcript saved in the transcription file on my computer to the media file in Dedoose and attached it to the respective participant ID so that all the data was associated to the specific participant. I created codes from within the deductive themes: family interaction, parenting, physical/material wellbeing, emotional wellbeing and disability-related supports, and the additional inductive theme community supports. I also used the best descriptive word for questions under each theme to create sub-themes.

Excerpting

Reading again from the transcripts, I highlighted excerpts from all transcripts in the media files that were best describing each theme and coded them under the theme. Within each of the themes I also inductively coded excerpts which formed new sub-themes. These sub-themes were either informed by the questions we had asked under each theme or were new from the additional information participants had given. In the end, all excerpts were linked to specific codes and to specific participants.

Presenting Analysed Data

Data analysis is presented in the next chapter. In summary, I analysed the demographic information, and then gave a deductive explanation of each of the main codes with verbatim extracts of the already set out domains of the Beach Centre FQOL Conversation Guide (i.e. family interaction, parenting, emotional wellbeing, physical and material conditions, disability-related supports and community supports).

4 CHAPTER 4: FINDINGS

4.1 Introduction

In this chapter, I will present the findings from the data regarding FQOL that was analysed from individual interviews with seven people with ID and eight caregivers, and two FGDs with the same participants from the three zones. The analysis is presented using the six themes that emerged from analysing the data deductively and inductively, namely family interaction, parenting, physical/material wellbeing, emotional wellbeing, disability related supports and community supports. The themes and sub-themes were downloaded as Word documents from Dedoose after deductive and inductive analysis. Each theme is presented using a graph depicting the importance of, priorities of supports and satisfaction for caregivers and people with ID. The graphs were downloaded directly from Dedoose based on participants' responses to these questions. They have been presented descriptively and presented using excerpts that support them.

4.2 Family interaction

Family interaction in this study was defined in the Beach Centre FQOL Conversation Guide as the roles that members living together in a home played while spending time together, helping each other, speaking to each other, and doing activities together, and how these influenced relationships among them. In this section, I present findings of all instances that caregivers and people with ID considered to be a reflection of family interactions together with the factors that made it favourable or circumstances that challenged it. Using supporting excerpts, I present the discussion under the sub-themes as illustrated in Figure 2 below.

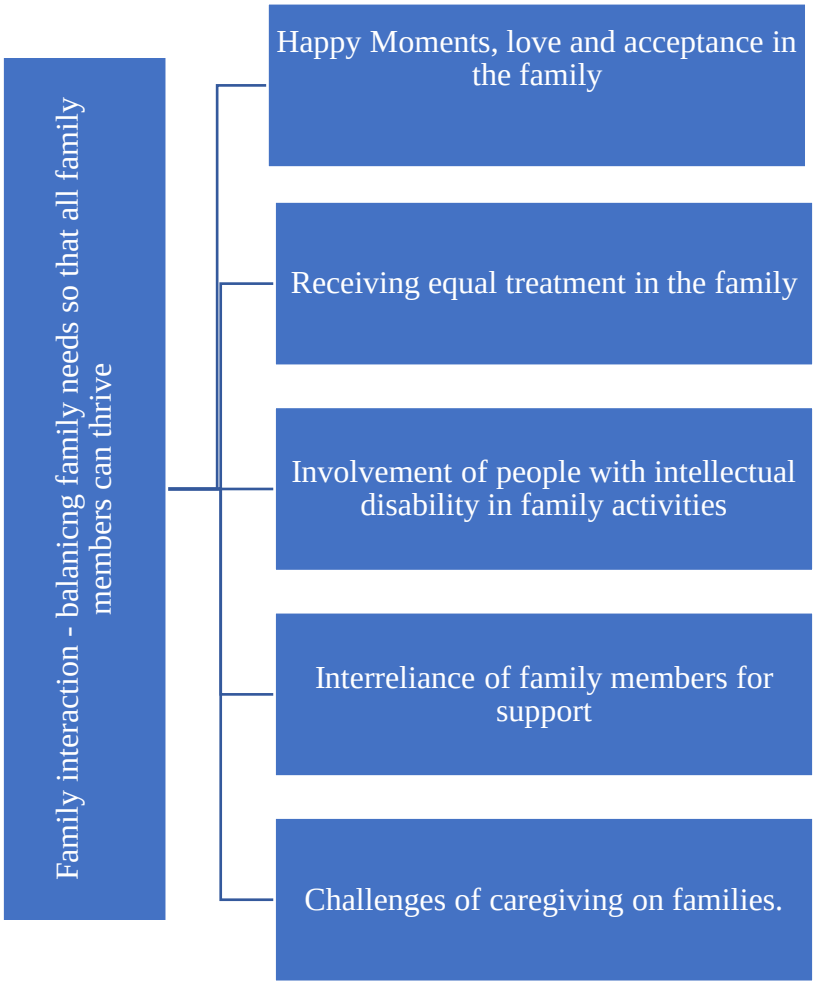


Figure 2: Themes and sub-themes of family interaction

The graph in (Figure 3) illustrates how participants perceived the importance of, priority of support in and satisfaction with family interaction.

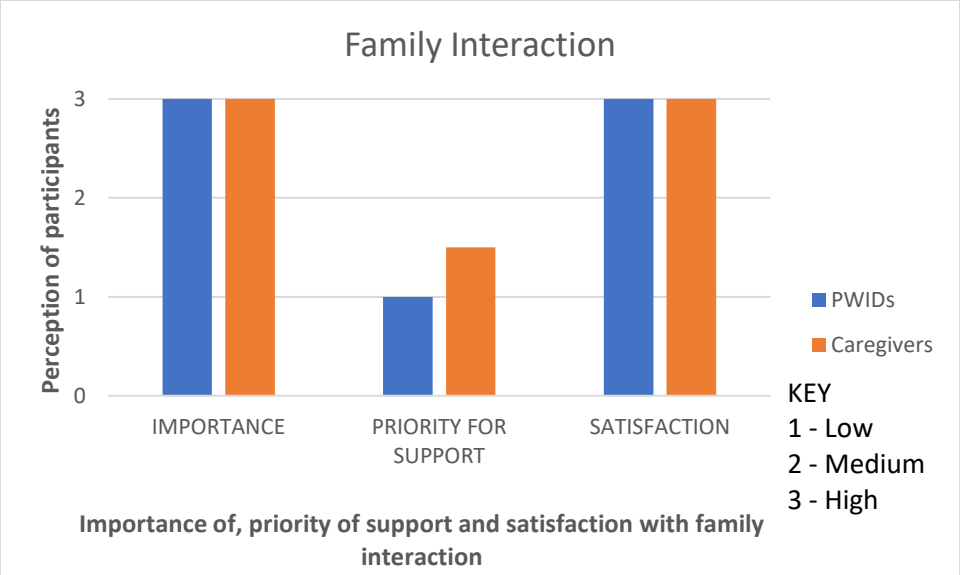


Figure 3: Importance of, priority of support in and satisfaction with family interaction

Both caregivers and people with ID in this study had very positive experiences with family interaction and hence expressed high satisfaction with this theme. Family interaction was considered satisfactory when members interacted well both in the small nuclear unit but even more when the extended family was involved. This was perceived as such because caregivers felt that they got opportunities to share with other family members and they received support in the form of advice on how to solve difficult issues,

> "When we are together as the larger family, we discuss many things and sometimes you get advice from the others about somewhere you may have been stuck" (CG1).

Caregivers expressed satisfaction with relationships in the family when they saw that the children are well accepted and loved by other family members (CG3).

4.2.1 Happy moments – love and acceptance in the family

Gestures such as supporting disabled family members in the community were viewed as expressions of love by caregivers and enhanced satisfaction with family interaction. "We all love this child and so we push her on the wheelchair around when we are walking outside" (CG4).

Family relationships and supports were regarded as being of utmost importance by people with ID. They felt that despite the need to progress in life, it was important for them to remain close to family members.

> "I'm well supported at home. It is difficult to think about having a life far from home. I love my family and we are used to each other. When I think about my future, I would like to work and be more independent but remain close to my family members" (PWID2).

Integration with the extended family was so important for families that when they lacked support, it felt like rejection for caregivers.

> "My challenge is that I'm an orphan and don't have brothers or sisters. When I have these children with me, I worry. My nephew sleeps here on the couch and I'm very ashamed but I do not have any means of making life better. My relatives abandoned us my aunties and grandmother. My family became too much of a burden for them to date. They rarely visit us or show concern about how we live our life" (CG8).

4.2.2 Receiving equal treatment in the family

Families were seen to effectively provide the balance in providing supports to people with ID as well as giving space for autonomy and growth in independence. People with ID expressed satisfaction with being treated the same as other family members through such actions as being provided with personal space at home where they could have privacy and autonomy.

> "I have my own little room where I relax when I want. This makes me very happy because I organise myself there. It helps me learn how to be independent" (PWID4).

4.2.3 Involvement of people with ID in family activities

People with ID also expressed satisfaction with being involved in routine family activities. They felt it created a sense of belonging and gave them commitments to their families as well.

> "I do a lot of work here at home. I know how to sweep the house, collect firewood, fetch water from the river, take the cows to graze in the field and cut straw and maize stalks for the cows. When I'm done with the cows I get the key, open the gate for the goats and take them to graze in the fields down the hill" (PWID1).

They felt that they only needed to be supported in activities they were not able to perform in the family.

> "It's my responsibility to keep my room clean and neat. I can wash my light clothing with the strong hand. I only rely on my aunt to pay someone to wash the heavier clothes" (PWID4).

Caregivers felt that activities at home helped the members with ID grow in independence and responsibility.

> "He knows the right time for milking and where to put the milk without help" (CG3).

It was also viewed as a motivation to engage in various activities which helped the members build their esteem and feel valued. By involving members with ID in family activities, caregivers felt that it helped to view them in the same way as everyone else, which deconstructed the disabled identity.

> "As parents, it would be good if we did not regard our children as disabled so that we shall include them in many activities. When we look at the disability, it makes us not involve them" (CG in FGD)

4.2.4 Interreliance on family members for supports

Family members relied on each other financially, for companionship and in provision of direct supports for people with ID. People with ID acknowledged that they required support from other family members from time to time to help them accomplish tasks effectively. Support by family members helped them get organised during the day especially when they required extra help due to sickness.

> "My mother and sisters help me when I'm sick. Everyday my mother tells me what I should do" (PWID1).

Family members also supported each other to manage financial constraints (CG4). However, circumstances did not always work out for them since sometimes it was challenging to find stable paying work.

> "Most of my children have gone to Nairobi to try and find jobs. A jobless person in the city has a tough life. In fact, they still get food from here to make ends meet. I cannot rely entirely on their support" (CG3).

Having family members with ID remain at home longer was also viewed positively as contributing to companionship to caregivers in old age when other siblings had relocated.

> "My child who has an intellectual disability is the only one remaining in the homestead since all the others have gone out of the house. I thank God because without him, this would be a very lonely place" (CG in FGD).

4.2.5 Challenges of caregiving on families

The main challenge expressed by caregivers was the strain on family members when they lacked support for members who required constant care. Family members had to make sacrifices to ensure the members with ID received support when they needed it. The need to remain at home to provide care meant that families had to forego income placing financial constraints on them. Alternatively, siblings had to forego schooling to allow parents to go to work while they provided care to the disabled member.

> "During school holidays, it is very difficult to manage care for our disabled daughter because we all have to go to work and the other children have to go for tuition. As the mother, it becomes so difficult for me to make sacrifice to stay at home. We need the money from my business because it supports schooling for the children and other family needs. Sometimes it's the children who sacrifice to go to school so that they can remain at home with her" (CG5).

4.3 Parenting

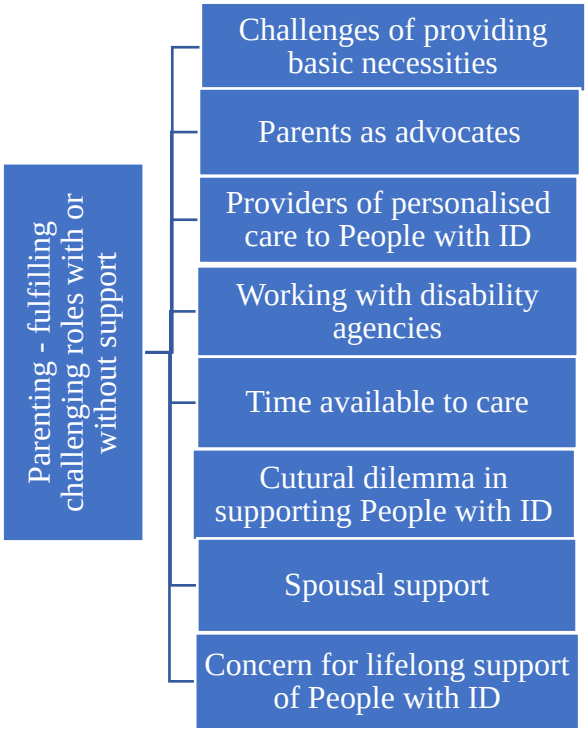


Figure 4: Themes and sub-themes of parenting

Parenting is a major role in the family unit which is defined in the Beach Centre FQOL Conversation Guide as raising children by ensuring their wellbeing, transmitting important values and preparing them for life. Parents offer the physical, material, financial, social and other supports required by their dependents to achieve their goals. In this study, parenting was viewed as an important aspect of FQOL, without which the family would suffer. People with ID were not interviewed on parenting role as none of them had a family of their own. However, they made important observations about the role they saw their parents/ caregivers play in their lives and this has been included in the analysis below. In this section, I present the findings on the importance perceived by caregivers of their role, their satisfaction with factors that helped them carry out the role effectively, and areas they prioritised as requiring supports. I will discuss the sub-themes presented in Figure 4 above supporting them with excerpts from the caregivers.

Figure 5 below illustrates the importance of, priority of support in and satisfaction with the theme of parenting as caregivers in this study expressed.

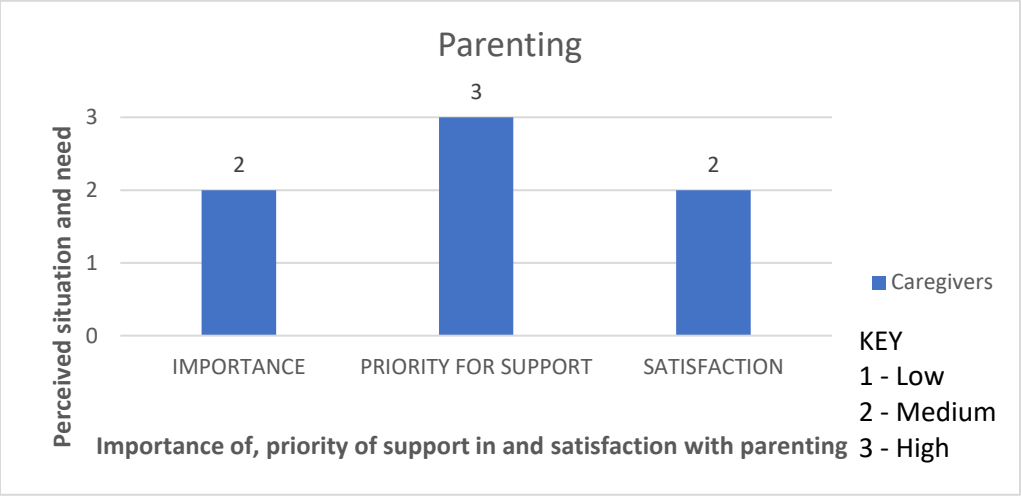


Figure 5: Importance of, priority of support in and satisfaction with parenting

The importance of parenting was reiterated by caregivers, who noted that in most cases they were the only ones their children looked to for any support they required.

> "As a parent, you might be the only one being looked up to for your children's needs" (CG8).

In this section, I discuss the factors that provided satisfaction in the parenting role and the areas they prioritised for support, especially financially, having knowledge and support from each other,

4.3.1 Challenges of providing basic necessities for the family.

Providing basic necessities for the family, however, was difficult for caregivers who felt they barely met the needs of the family sufficiently, let alone the additional needs of individuals with ID.

> "Life is so difficult. My children don't know sugar and they don't mind eating boiled maize, porridge or potatoes whatever will be available for the day. Once we are satisfied we can go to sleep and wait for another day" (CG2).

4.3.2 Parents as advocates for people with intellectual disability

Parents recognised their role as advocates for the people with ID within their own communities. Some felt it was their responsibility to ensure that neighbours and visitors understood their

children's conditions and way of life so that they were not misunderstood or mistaken for being wayward.

> "Educating people without disability about those who have one is important for disabled children to relate with them" (CG6).

Participants with ID felt that caregivers had important roles in affirming them, strengthening their concerns and advancing their plans and hopes for future engagements. They recognised the role their caregivers played in supporting them to realise their dreams, helping them find greater clarity in their ideas, prioritising their day-to-day issues and the direct support they needed to achieve their goals.

> "Our parents discuss with us so that they can strengthen our concerns and help us achieve our goals" (PWID in FGD1).

Additionally, caregivers felt they were strategic in the provision of protection to individuals with ID at home and in the community, sometimes mediating misunderstandings and the rights of their members. This gave the disabled members an impetus to demand respect from people who undermined their dignity or showed them disrespect.

> "He recognises when people don't treat him well. For example, he tells his grandfather to stop handling him like a fool. He always asks me to arbitrate and insists that his grandfather should change his attitude especially when he tells him something or corrects him furiously" (CG3).

Caregivers felt that a lack of information about disability by their neighbours posed risks, as their children's actions could be misinterpreted and they could sometimes get punished for it. They therefore felt they had a responsibility to educate the community.

> "We as parents first need to get the people around us like our neighbours, to know about our children so that they can understand them. It will reduce the chances of risking danger such as being beaten when someone did not understand when your child speaks or acts out of ignorance" (CG7).

4.3.3 Providers of personalised care to individuals with intellectual disability

Among the daily roles that caregivers engaged in, support for members with ID was a priority. This involved support in making good choices and decisions in the activities of daily living such as dressing, feeding, and bathing.

> "You have to tell him the difference between dressing up presentably to go to places like church and dressing up to go to the farm. He requires support making such decisions' (CG3).

Caregivers who had children with complex needs felt that the task was overwhelming when they were left to handle it alone in the family, which could lead to their neglecting important issues.

> "Parents require support especially if they have a child with special needs because they have more needs. It's easy to ignore some important issues because the needs are overwhelming" (CG8).

4.3.4 Working with disability agencies

Caregivers expressed the need to be given information that would help them provide good care, especially when a child had complex impairments that required constant attention. Working with other programs in the community that provided disability services helped them with support and advice.

> "We wanted our son to join the local polytechnic but the social worker discouraged us from doing so. He advised us to let him remain at home to get used to doing manual jobs and find out his interests from here. Later we can then find the suitable course which he can enrol in at the polytechnic, building or carpentry" (CG3).

4.3.5 Time available to care

Because of the need to provide materially for the family through work, most caregivers could not get sufficient time to provide personal care during the day.

> "Regarding care for the disabled one, it is difficult to balance work and staying at home with her so sometimes I make compromises and leave her in the house" (CG5).

To balance the need to provide care and work, caregivers devised strategies such as setting routines for their disabled children, so that they knew when they would be receiving support with

feeding, changing, toileting and company. It helped the caregivers manage both responsibilities in a way that, according to them, wasn't punitive to their children.

> "I have challenges with being there for my daughter the whole day. I developed a programme for her where she knows what time I will be home for her changing and feeding and I stick to these times. This programming of myself and for her lessened the stress she would have crying when I did not manage to be home when she needed me. She has adjusted herself to this" (CG1).

However, a lack of time to give support was seen to affect the manner in which caregivers helped members with ID learn important skills that they required at home. They noted that a lack of time impacted negatively on their disabled family members who had potential skills that were not harnessed due to a lack of attention and guidance in activities such as cooking.

> "I was advised by the social worker to involve him at home in house chores and we have been doing that. I'm not so committed in it because I feel that I have other more pressing concerns like finding work and so we have not made much progress on that" (CG2).

Skills development at home was also challenging as caregivers observed that the members with ID sometimes lacked interest or determination or refused to learn (CG7). Caregivers also felt that it was challenging to help their members with ID learn, especially if they had more than one disabled member in the house. The challenge noted was because of the different care needs that each one required, as well as the other responsibilities they had to carry out in the family.

> "It is very difficult especially because I have both Peter and his mother with the same condition. Their support needs are very different and I cannot meet all of them. Sometimes we compromise their needs because I'm unable to offer them the best support" (CG3).

4.3.6 Cultural dilemma in supporting people with intellectual disability

Some cultural issues were difficult for caregivers to decipher how to address them. One example was the issue of going through the rite of passage which culturally signified that one had entered adulthood. The significance of this ritual is that an individual assumes total independence, including having their own house away from the family house. Caregivers had difficulties

making decisions about whether or not to have their family members with ID follow this cultural obligation, noting that they would still be dependent after the rite.

For the disabled person, failure to undergo the rite of passage meant that they were viewed as underage, which denied them adult privileges in the community, therefore increasing stigma.

> "I'm stuck regarding the issue of letting my son who has intellectual disability go through the rite of passage because culturally at his age, I should have him become more independent with his house outside our main one. Traditionally, it is the role of my husband to follow up the issue of going through the rite of passage for our son with intellectual disability. But he is not concerned because of our son's disability. He has delayed and I would like to be advised how to go about it especially because he will remain dependent on us even after the rite of passage" (CG2).

4.3.7 Support by spouses

Some of the caregivers who were mostly mothers felt that they did not receive much support from their spouses when it came to issues of the disabled child. Neglect of the family was a major cause of stress in parenting and some caregivers were completely abandoned, having to manage the family alone. Some caregivers attributed this to having a child with disability for which they were blamed, while others felt it was because of poverty. Poor spousal support by fathers left families vulnerable and at risk of breaking up.

> "My husband is not supportive. I have challenges and it's difficult to be a good parent in my situation. He does not take responsibility for the family. Without support from my husband it's difficult. He doesn't show concern for anyone in the family. He comes home late at night, goes to watch movies and leaves us without food in the house. I am so confused, I don't know what to do. Many times, I have threatened to leave but he never changes" (CG2).

4.3.8 Concern for lifelong supports for people with intellectual disability

Caregivers felt that providing care to people with ID as they grew older became more challenging than when they were younger.

> "When the person with disability grows older, parents feel more burdened if they have to remain with the person at home. When they are young children, it is easy to go with them wherever you want. When they are older they sort of become a burden. Some parents even despair" (CG6).

Concern about the future was also shared by the individuals with ID.

> "My aunt is growing older. I worry about the future and how my life will be without her" (PWID4).

Caregiver concerns included the need for lifelong supports due to the uncertainty of life trajectories, and acquisition of life skills such as using money and transition into adulthood, among others.

> "As a parent of a child like Peter, my worries are around his future. What will it be like. I'm really worried about what will become of his life when he grows older. My son is 18 years old and I'm worried about his future. He doesn't know how to count money and I don't know how he will manage adulthood. If I would know what I can do so that he can help himself then I would do it. As parents, we are not waiting for him to gain anything from education so we are really stuck on this issue" (CG7).

> "Let me say that I'm worried about their future because I'm growing older and I don't know what their future will be like when I'm not there to support them. I only do the much I can because now I'm old. I cannot manage to do a lot of work" (CG3).

4.4 Physical/Material conditions

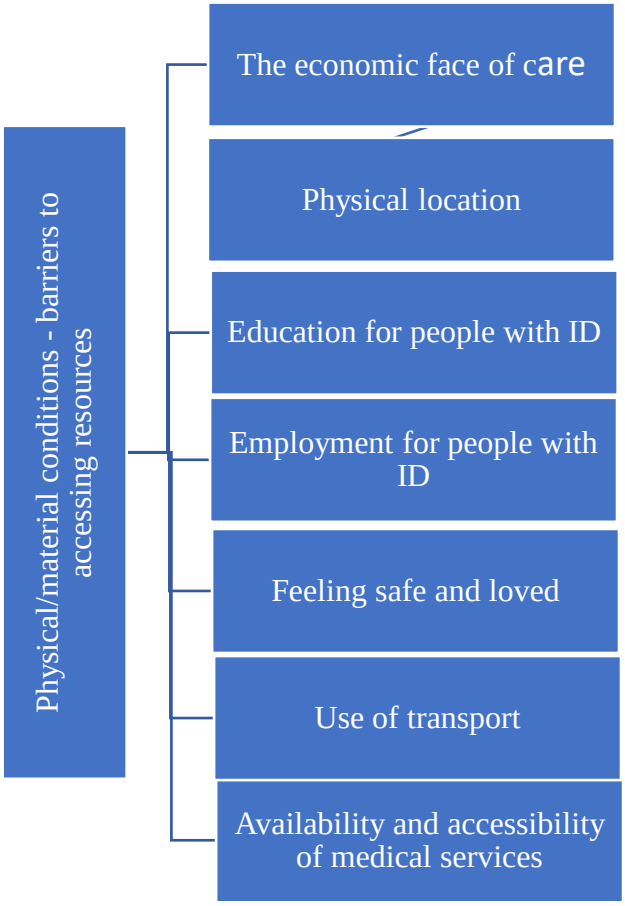


Figure 6: Themes and sub-themes of physical/material conditions

Physical and material conditions are the resources that were available to families in this study. Figure 6 above is a representation of the themes and sub-themes discussed below regarding Physical and Material conditions using supporting excerpts. In this section, I present the findings of the importance of, priority of support in and satisfaction with that participants had with physical and material conditions. Figure 7 below is an illustration of how participants perceived the importance of, priority of support in and satisfaction with physical/material conditions in the family.

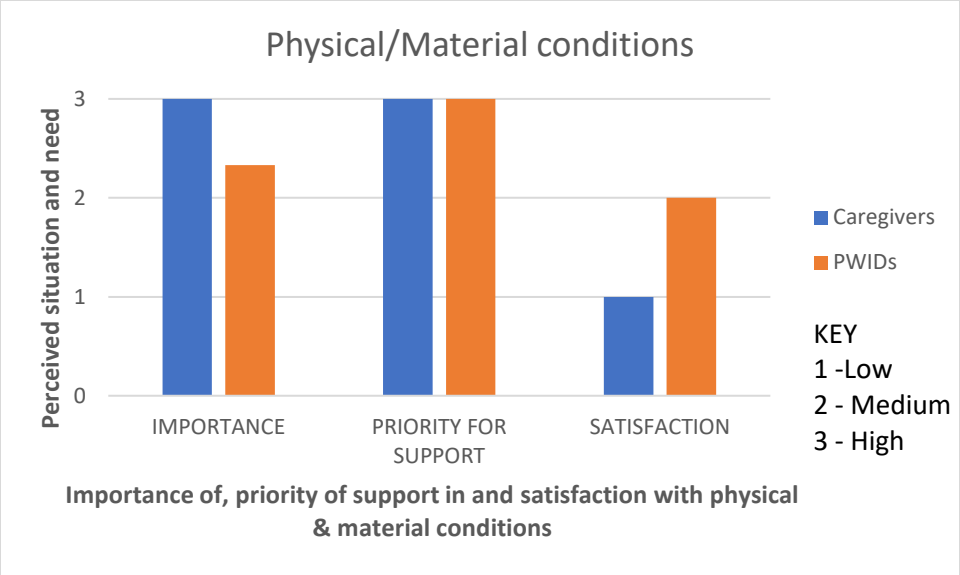


Figure 7: Importance of, priority of support in and satisfaction with physical/material conditions

According to participants, the importance of physical and material conditions was being influenced by factors such as location, education and employment of people with ID in this study's context. These have been discussed below. Both caregivers and people with ID placed high priority of support in physical and material conditions for the family. Satisfaction with physical and material conditions was lower for caregivers than for people with ID, which can partly be explained by the fact that caregivers had a bigger responsibility to provide for the needs of the family.

4.4.1 The economic face of care

The situation in many families was one of dire material need. Most of the caregivers in this study were low income earners relying on casual work or small businesses to meet the expenses of their daily needs. Most casual work was found in farming and, according to caregivers, this was not a reliable source of income as it was very seasonal.

> "You can have two good weeks where you find work at least 4 days followed by a week without any work. During harvesting period, you can find a job everyday with a daily pay of Ksh 200 (approx. USD$1.5). When there's no farm work it's hard to manage. In a year ploughing, weeding and harvesting times give us some assurance of finding work, the rest of the year is hard to manage" (CG2).

Caregivers were deeply dissatisfied, mainly with their financial situations, because it limited the basic needs provisions they could make for their children.

> "The challenge is not that the children are misbehaving but because they are not getting enough food in the house and I am not finding work easily and so they can go for days without food. That is why they started going to the streets. It's common to find his clothes blood stained. People slap him a lot. He has recently become accustomed to ask money from people to buy himself food because there are days we have nothing in the house to eat" (CG2).

Economic constraints in the family also interfered with the ability to make choices for people with ID whose needs were likely to be seen as secondary. This impacted on the manner they received other support for their needs and sometimes limited their functions.

> "Sometimes it is not possible to buy things we need in the house and cater for my personal needs" (PWID6).

This sometimes-created conflict with caregivers when they were unable to provide for all needs.

> "Sometimes children ask for something I can't afford and sometimes the things they ask for will cost a lot of money. For example, buying toys while we have other more basic needs like food. Financially we become constrained to meet all their needs. The child with a disability has more needs than the others and sometimes it's difficult to manage them. He always insists you have to buy. He doesn't know that sometimes you don't have money. He believes you always have money and that is a challenge" (CG7).

4.4.2 Physical location

Some caregivers preferred to live in urban areas because of the possibility of employment opportunities.

> "We would love to have sufficient money to be able to support this child well, so we stay in town where business is better" (CG3).

Living in close proximity to various social services was also important for families in order to access the services they needed easily.

"To live in a nice place in a good neighbourhood. A place where you have majority of services you need. For example, a place where you find water for farming, a place you find space for gardening. A place close to health facilities, where I can take my children to hospital when they need" (CG7).

However, this choice forced families to take up shelter in informal dwellings where the situation was deplorable.

"Our house is small and we sleep on the floor with my children and cover ourselves with the blankets. The house is very cold, my husband just put cardboards on the inside recently" (CG2).

4.4.3 Education for people with intellectual disability

Caregivers expressed the desire to provide good quality education to their children for a good quality of life (CG2). However, providing education to individuals with ID was challenged by cost and the lack of quality.

Cost of schooling

Caregivers in this study felt that costs related to schooling for family members with ID were exceptionally high and barely affordable, especially because there were additional costs involved for personal effects required by institutions.

"(*Long silence* ….) It has been very difficult to afford the support required for our daughter (*sigh* ....). For example, she is on medication that she cannot do without, we also have to buy pampers all the time. So, in terms of money, we spend a lot on her care. When it comes to the cost of her school, her expenses are too many especially in buying pampers. The school asks too much fees and personal effects for her. Most of the time we sell chicken and goats to manage some of the needs" (CG5).

Caregivers felt that they made lots of sacrifices in the family, just to ensure that their members with ID went to school.

"Huh! That is difficult. First of all, providing her needs for schooling like the uniform, personal effects are barely manageable. I have a salary of Ksh 5000 (*equivalent to approx. 50 dollars*) per month. We have to make a lot of sacrifice in the house to afford to keep her in school" (CG8).

Quality of education

The quality of education for people with ID was a challenge as it mostly only offered skills around routine activities of daily living.

> "Our children with disability tell us when nothing happens in school. Parents despair when the education of their disabled child does not improve and yet they have put so much effort to take them to school. They only seem to get trained on how to stay clean, to groom, they are fed and that is it" (CG6).

Caregivers expressed desperation when their children did not gain a lot from an education they had invested a lot in.

> "My child just goes to school to pass time because nothing much happens in school. She has not gained any skills" (CG5).

People with ID saw this as a form of discrimination and exclusion when they did not receive a quality of education that would be of benefit to them.

> "People with disabilities in special schools are not treated well. Some of my friends have spent a lot of time in school and for what? The teachers have the impression that we are not interested in education. The quality of education for us is poor since we are viewed as not capable of helping ourselves with it. Those are the things that make us feel treated like useless people. We are treated like [outcasts]–*nitwateaniirio"* (PWID2).

Some caregivers noted that taking their disabled family members to school was inconsequential as they would end up spending a lot of money, disrupting family rhythm and, in the end, have no tangible results from the period their children spent in school. As a result, they preferred remaining home with their children and tried other economic ventures that would engage their children.

> "I decided that it was not a good idea to take my child to school to do away with the burden of care yet after two or three years she would be back home. It would be deceptive on my side to think that this will help me. I decided in my heart that it's better for us to just live together within our means. Even if I could afford to take her to school, I would rather do something else to benefit our lives like buy a cow that will provide us with milk and give us nutrition and income for our needs." (CG1).

4.4.4 Employment for people with intellectual disability

Participants with ID felt that having work meant that they exercised independence. This was also an opportunity of social interaction in different environments. With an income from employment, they felt they would be able to make choices in the things they wanted in life.

> "I would really like to have a job to be independent and do the things I like. If I could get a job where I'm leaving home in the morning and coming back in the evening it would be an opportunity to visit places. A job would help me make money to buy nice clothes, shoes and the things I like" (PWID5).

Caregivers said that their family members with ID often shared their dreams to plan their future in the same way other members of society did.

> "You know, my grandson would be happy to live like the other people. Having his own things, his own house. I usually ask him what he thinks about his future and whether he would like to have a wife and he tells me that he very much would like to marry and have his own child. He thinks about it." (CG3).

However, individuals with ID felt completely shut out from income generating activities by society. This was in part attributed to the fact that their education did not deliver the results they hoped for. The lack of employment opportunities was disenfranchising for them because it limited their ability to make plans and isolated them from engaging in life the way other members of society did. They felt that this discourse maintained them as dependent solely on their caregivers, even though they felt capable of having independence through their potential abilities.

> "I feel that it is difficult for me to plan for tomorrow because I don't have the opportunities a person without disability has. I find it difficult to always depend on my parents in everything even though they are willing because I know I'm able to work and earn a living. They should help me only partially" (PWID2).

In some instances when they received economic empowerment, they criticised the nature of work for failing to treat people with ID on an equal footing with other members of society. The said interventions maintained the notion that they were unable to do other jobs and maintained a disabled identity.

"Organisation X bought me a goat as capital for economic empowerment to support me but it is not enough. I need to be treated like the others" (PWID4).

4.4.5 Feeling safe and loved

Apart from caregivers who lived in the informal urban settings, the majority of the participants felt that they were safe at home and in the community. Caregivers also felt that community members showed respect to individuals with ID and did not demean them with words or actions. People with ID approved of feeling safe in the community.

"This place is safe enough. I do not worry about her safety. I close my business at night and still walk home" (CG5).

"We've never had any problem with security here in the community and you can never hear even the slightest mean word" (CG4).

"I'm safe at home and in the community. There's no problem with safety. I can move around without problem" (PWID4).

Caregivers were mainly concerned about environmental hazards for and disorientation of family members with ID who would not be able to return home by themselves if they happened to wander away. This raised the need for having individualised support for disabled members to manage movement within their environments free from encountering accidents. Without support, family members with ID were kept safe by confining them within the house or homestead.

"Normally I leave her locked in the house because I can't leave her outside. It would be dangerous for her probably she could fall into a ditch or get lost and she cannot be able to say where her home is or bring herself back. And because she has severe disability, I leave her alone inside the house but I ensure she is safe" (CG1).

4.4.6 Use of Transport

Caregivers and people with ID could use and access public means of transport with ease. However, travelling was not common due to economic constraints (CG2). People with ID expressed concerns about getting individualised support to walk or use public transport for their personal safety and payment of fares.

"Some situations can put us in danger even if you are independent. Walking on the road in town where motorcycles and cars are moving fast is dangerous for me. If I do not have

someone to help me cross the road, I prefer to remain at home. I usually travel by matatu (public transport). But I have to be with someone. I don't know how to give the correct fare" (PWID3).

Some individuals in the study had never travelled by public means because they were not engaged in any purposeful reason to travel.

"I have never gone anywhere by car. There's nowhere to go. I just stay at home. I don't have a place to go" (PWID5).

A lack of adaptive devices such as wheelchairs for people who needed them for transport also hindered travel. Carrying a heavy individual was cumbersome for caregivers, who opted not to travel or to leave the disabled person at home when they travelled, especially when they needed to walk long distances.

"She hardly uses public transport because she's too heavy to carry. Because we use bodaboda which is not comfortable, we choose not to bother her unnecessarily. It would be a big hustle to travel with her especially if you will be forced to walk some distance" (CG5).

4.4.7 Availability and accessibility of medical services

Medical services were availabile and accessible to people with ID and caregivers.

"I am able to go to hospital whenever I'm sick. I'm able to explain my problem to the doctor and they understand me well. I am given medication without problem" (PWID2).

Success with medical care could be attributed to the national medical insurance cover for families offered by the state, and waiver of services in hospitals.

"I have an NHIF card therefore I'm well covered medically with my family" (CG8).

However, other health services such as Physiotherapy or Occupational therapy were not easily available in rural settings for participants in this study with multiple impairments who required them. Families expressed challenges with managing difficult conditions and felt there was need to have the services closer to them.

"It's very difficult to receive therapy for our granddaughter nowadays. We were told to be doing it at home but sometimes she's very stiff that nobody is able to do exercises to her" (CG4).

4.5 Emotional wellbeing

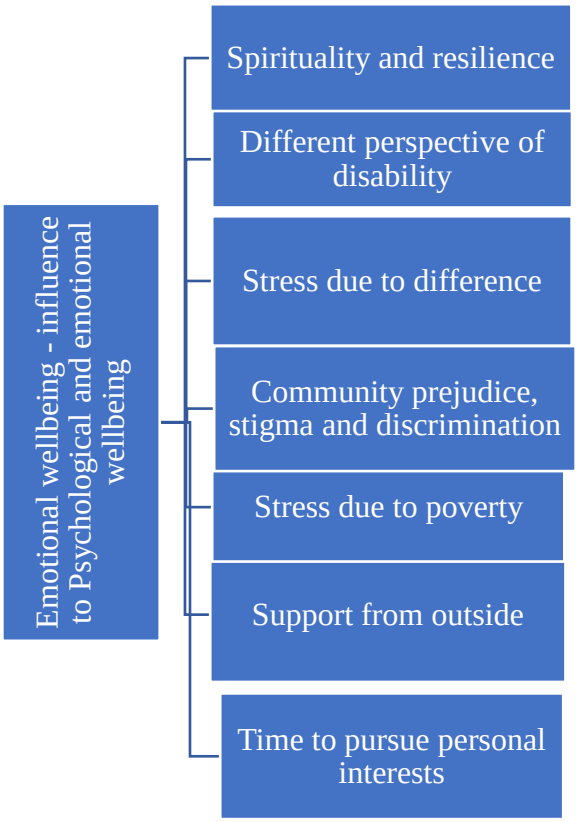


Figure 8: Themes and sub-themes of emotional wellbeing

In this section, I will discuss the dynamics of thoughts and feelings that caregivers and people with ID described as their day-to-day experience. There was a significant difference in the way caregivers and people with ID perceived their emotional wellbeing. These differences are discussed below using the sub-themes presented in Figure 8 above.

Figure 9 below illustrates the perception of participants on their importance of, satisfaction with and priority of support with emotional wellbeing.

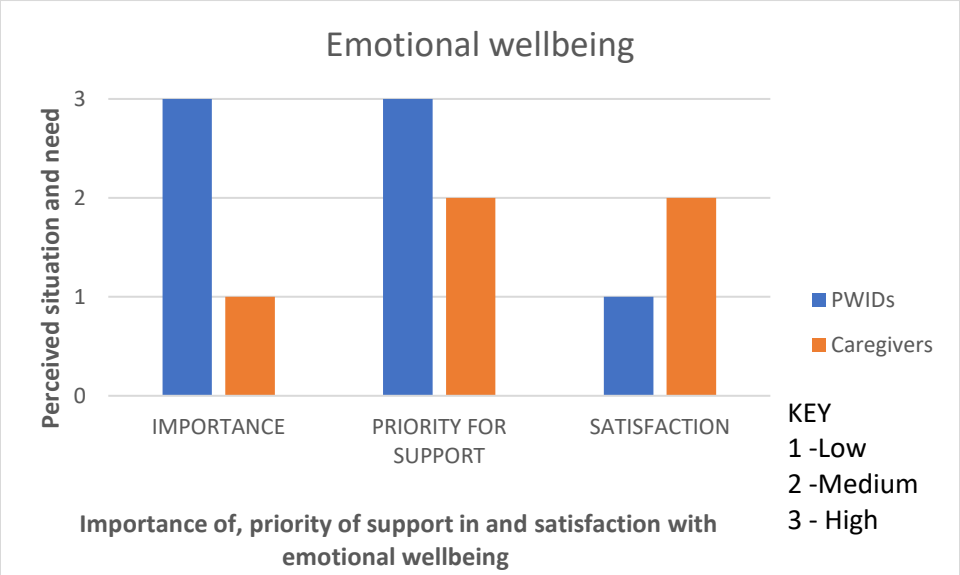


Figure 9: Importance of, priority of support in and satisfaction with emotional wellbeing

The importance of emotional wellbeing was higher for people with ID than for caregivers. People with ID had low emotional satisfaction owing to the fact that having an impairment caused them to stand out in ways that made them prejudiced by the community. They therefore sought a high priority for support in helping them adapt in different situations as well as in the way disability was perceived in the community. Caregivers, on the other hand, had little concern over their emotional welfare, citing the need to be there for their members. In a sense, it seemed that they sacrificed their emotional health in order to support their disabled family members. They seemed to derive satisfaction with their emotional wellbeing on spirituality and resilience. Therefore, caregivers were relatively satisfied with their emotional wellbeing and didn't have expectations from outside or professional support. What seemed to impact their emotional wellbeing negatively was poverty expressing the need for practical supports.

4.5.1 Spirituality and Resilience

Care had a significant spiritual meaning to caregivers, from which they drew strength to provide it every day. For some caregivers, having a disabled child was not a negative thing, as was commonly conceptualised by society. It was rather viewed as an opportunity to be of service to the disabled family member who they perceived as contributing to their human nature. This contribution in spiritual terms was viewed as being of infinite value and a lesson towards

enhancement of human relationships. They also described the experience as one that brings the experience of God closer to human nature, which is often perceived in abstract terms.

> "In our community, disability seems like a very absurd thing to happen to a family because we do not want it. My child on the contrary gives me the opportunity to serve. This is a God given gift and it leads to eternity. If I were to look at what is most valuable for me in life, this is one thing I would say is of utmost importance. I look at it now, not just for my child but I think it is the way I should be with the other people. The peace I receive by giving service to my child is an important difference although very hidden. It is an opportunity to serve, something we all need to understand and grasp and it is about knowing God. It is what that gives peace" (CG in FGD).

> "It is true that our disabled children are important. They help us to understand God among us. It is difficult to understand God but they help us understand God in some way. Caring for them willingly keeps our conscience and intentions pure in a way although that has not been easy but it helps me as a person. That practical way of giving care that can be exhausting has given me a little bit of understanding of God. I dedicated good time for caring for my child knowing that it is also helping me" (CG in FGD).

4.5.2 Different perspective of disability

Having an impairment was not viewed negatively by caregivers. The direct experience of having a disabled member in the family helped them recognise disability as a state anyone could get into. They therefore understood the importance of treating disabled members with the same dignity they would like to have. Depriving care to someone in need of it was viewed as negating their own existence or being in denial of something that they would embody anytime.

> "The reality is that disability is part of us. The problem for us is that people don't think they can get disabled any time. They don't give it a thought because it does not concern them if it has not happened to them. For us who have these children, it is a reality everyday. If we mistreat or mishandle them, we are doing greater harm to ourselves" (CG in FGD).

4.5.3 Stress because of difference

People with ID, on the other hand, placed high importance on emotional wellbeing. They were concerned with the fact that impairments gave them obvious physical differences that made people look at them differently.

> "I ask myself why I'm different. When I take long to say something that I wanted to mention easily, I'm worried about my tongue. I feel bad. I would like to speak faster" (PWID1).

They expressed dissatisfaction in terms of the impairments causing them to miss out on social interaction, which resulted in loneliness.

> "My language is not very clear, so it may not be possible for people to understand me well. So, I don't have friends" (PWID4).

For the majority of them, their lives revolved around being at home with family members or just their parents.

> "I've stayed at home for so long. It has been so long. Now we live with my father. I think about so many things. Nowadays I come to the shopping centre just to see what people are doing. Outside home, I do not have a lot of friends or support. I have never seen anyone who is interested in me. We are at home only with my father and it's very lonely" (PWID3).

4.5.4 Community prejudice, stigma and discrimination

Although in parts of Kinamba and Nyahururu people with ID felt safe and loved, in some neighbourhoods in Nyahururu and Ol'ngarua, caregivers cited the community's negative perception of disability as contributing to stress.

> "I'm satisfied with my child and our life but the challenge is that we operate in a society that does not accept us" (CG1).

Caregivers felt that people with ID were not regarded as part of society.

> "They even don't regard her as existing. Nobody has ever asked me about her" (CG8).

Cultural beliefs upheld in the community viewed disability as caused by curses, witchcraft or something bad done by the family.

> "Most parents are asked by their families to find out the cause of disability for their children and this causes stress because it is believed mostly that either it was a curse, bewitched or something wrong with the family. So, parents can spend a lot of time in life trying to find out about this causes that are believed to cause disability and seeking help in the wrong places from the wrong people" (CG1).

Being disabled was viewed as undesirable by community members and it provoked negative reactions such as pity or dismay. For example, people viewed disability as contagious and would react by moving away or keeping at a distance once they realised they were in close proximity to a disabled person (CG6). People with ID would be publicly disparaged in communal settings.

> "Sometimes my daughter will tell me, 'Mum, I was in a place today in town and people were just staring at me. One person said, look at a small girl with such big breasts and she's dragging her feet while walking'. People stare at her most of the time and with the sexual abuse it is humiliating. She knows that people regard her differently are mean towards her and she reports it to me" (CG8).

In some instances, vilification from peers often made people with ID abandon their goals, which contributed both to disenfranchisement and isolation.

> "I was training in wood work but I don't like going to the polytechnic. The other students were laughing at me and mocking me so I stopped going there. They were insulting me at the polytechnic" (PWID5).

People with ID also dropped out of local schools close to their homes because of stigma when children in mainstream schools could not accommodate them. The circumstances forced them to go to boarding schools away from home, which had financial implications on already constrained families.

> "My grandson used to go to a nearby school but the teacher asked him to remain at home because other children used to fear him because of epilepsy. We have to take him to a boarding school far away" (CG in FGD).

Discrimination was prevalent even from administrative structures that people with ID expected protection from. Being labelled 'intellectually disabled' automatically excluded them from participating in communal activities.

> "You will find that the village elders do not listen to them or give them an opportunity for work or participation in any forum. Simply because they think they are not capable because of intellectual disability" (CG in FGD).

4.5.5 Stress due to poverty

The state of deprivation in families was a huge distress to the caregivers and seemed to get magnified by the need to offer other support to the intellectually disabled individuals.

> "I feel under too many trials and I wonder if God created me only to have problems to this extent. I look at how much my children are suffering too, we sleep on the floor without mattresses. I ask God why my child with a disability cannot become intelligent and go to school like other children" (CG2).

4.5.6 Support from outside

Participants in this study were not familiar with professional psychological support for their needs (CG3). Even regarding issues of disability, caregivers did not feel the need to seek support from friends. This could be attributed to the negative attitudes in the community towards disability. The only support that was sometimes considered was financial help.

> "Rarely will you get such support from friends. There are different kinds of problems. Some issues are personal while others require the attention of the community. For issues arising from people with disability, that is considered a personal problem. You can only seek financial help from people for their needs" (CG3).

They believed that friends were in similar positions of need and would be difficult to get help from.

> "What will friends help you with? My friends are just lowly people like me" (CG8).

4.5.7 Time to pursue personal interests

Caregivers expressed satisfaction with emotional wellbeing, viewing care as a personal responsibility. This view seemed to be a suppression of their own feelings, while wanting to remain altruistic to their family members with ID.

> "It is true I have a big responsibility in caring but my work is my responsibility. I don't get tired of doing it. It gives me satisfaction so I'm determined. My responsibilities are my personal interests" (CG3).

Relying on each other to support the disabled member helped family members have personal time to pursue their own interests while others took care of the member with ID.

> "We are able to have personal time because we just plan ourselves and take turns about who will remain at home with the child. We can say that for us we are able to pursue our personal issues because of supporting each other. It's not just us as grandparents who support our daughter but her brothers and sisters usually give a helping hand. They will ask to spend some time with the child at their homes" (CG6).

However, in some instances, caregivers recognised that they experienced burnout, which sometimes could have adverse effects on their emotional wellbeing, for which they required support.

> "I feel that parents do require to have moments they are sharing about their difficulties when they are stressed. Some of them kill themselves when things become too difficult" (CG4).

For people with ID, personal time was viewed as when they engaged in recreation. However, such moments were viewed as very limited because of a lack of social networks and hence they did not have a range of ideas of how to spend their personal time.

> "I don't know many things to do for leisure. I have a lot of time that I spend probably looking after the goats or sweeping the compound and cleaning up my room. That's how my personal time is spent or just relaxing alone at home" (PWID4).

4.6 Disability-related supports

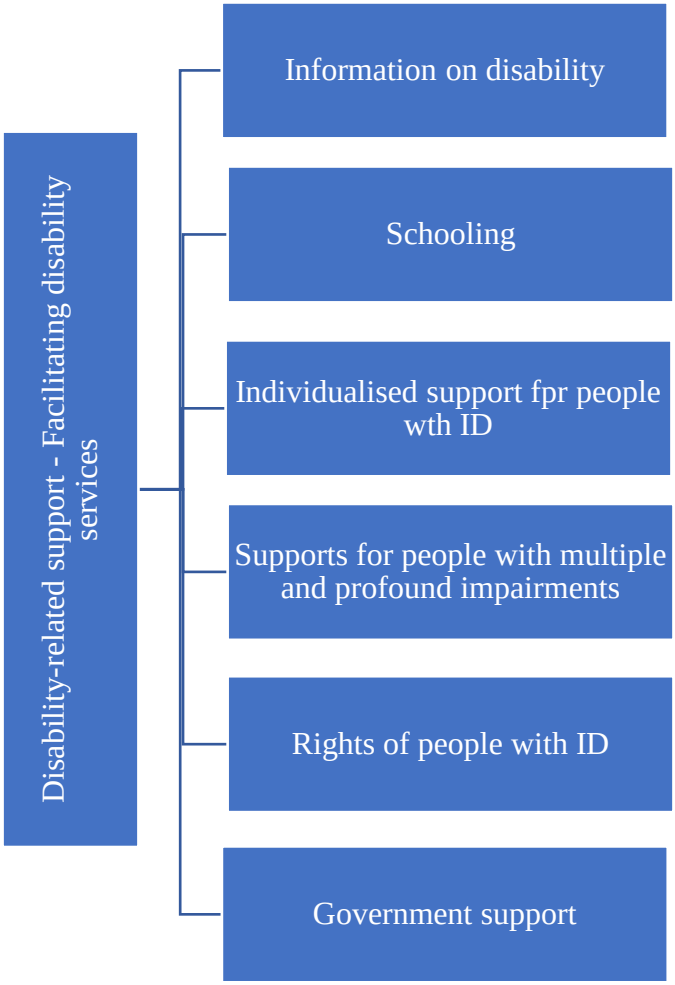


Figure 10: Themes and sub-themes of disability-related supports

Disability-related supports was the opportunities and services that enabled caregivers and people with ID to go about their daily activities effectively. In this section, I present findings on the importance, satisfaction and priority caregivers and people with ID placed on disability-related support. What arose as the sub-themes in disability-related supports were the need for information on disability, schooling, support with work for people with ID, supports for people with multiple impairments, recognition of individual rights, and government support. These sub-themes are discussed using excerpts from participants.

Figure 11 below illustrates the importance of, priority of support in and satisfaction with disability-related supports according to people with ID and caregivers.

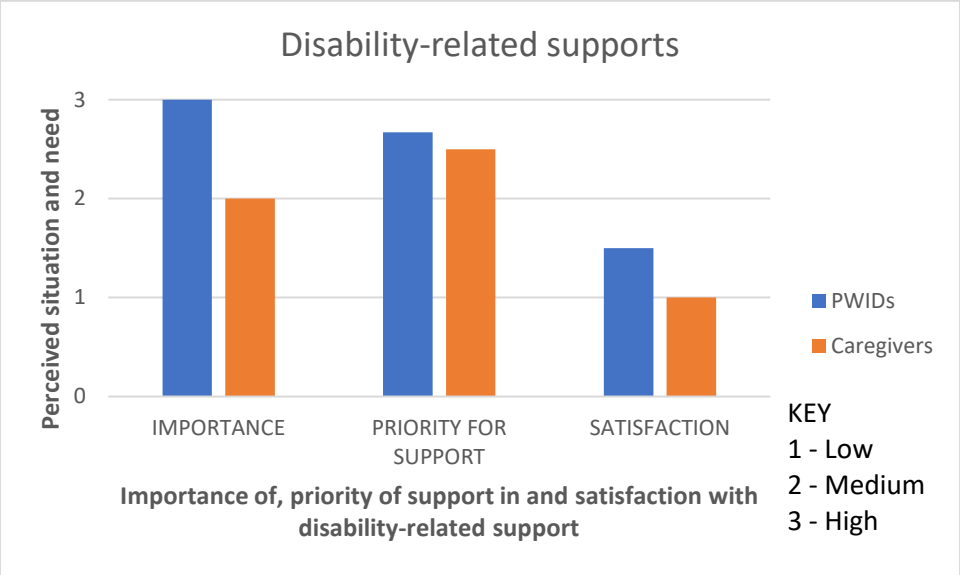


Figure 11: Importance of, priority of support in and satisfaction with disability related supports

Discussing disability support was recognised as important by caregivers as well as individuals with ID. The importance, priority of support and satisfaction with disability-related supports were influenced by information on disability, notions of individualised supports, medicalisation of ID, Rights of people with ID and government contribution to services of people with ID.

Caregivers felt that there were very few instances of disability-related supports and that both they and the community around them had a poor conceptualisation of supports. Caregivers saw the study as an opportunity to explore their own conceptualisation of supports.

> "You have made me think more about my daughter and even know that I need to know more about my daughter. I did not know they need support" (CG8).

People with ID felt that supports was of high importance to help them make progress in life and was hence a high priority.

> "People with learning disabilities like myself and my mother need help to be get good skills for work. If you give a little help, tomorrow you will notice a good change and this helps us" (PWID6).

4.6.1 Information on disability

Caregivers attributed the lack of supports to limited knowledge of ID (CG2). Further, there was a feeling that professionals themselves sometimes did not understand ID and therefore were unable to discharge their duties effectively.

> "In the hospitals, I see that even doctors do not know about disability well. Some will refer you to bigger hospitals for a small sickness just because they saw your child has a disability, or just scribble a diagnosis and medication without doing tests. They are anxious about disability and fear to prescribe medication" (CG6).

Without a good understanding of ID and associated conditions, caregivers felt incapacitated to provide supports efficiently.

> "My daughter is difficult to understand. It's difficult to understand how her mind works. It's difficult to train a child like her because she has Downs syndrome and we are not trained as parents on how to manage it" (CG8).

Having the right information was perceived to contribute to fewer psychological problems and provide ease for families to manage their disabled members.

> "The people who give information about disability should be trained to give the right information to reduce the amount of stress parents go through" (CG4).

4.6.2 Schooling

Schooling was viewed as an important aspect of growth for individuals with ID. Caregivers observed that through schooling, people with ID learnt a few activities and were socialised. School also offered an opportunity for interaction with peers.

> "The first thing I noticed when he went to school is that he learnt how to play with other children. He never used to play. In school, they teach them how to socialise. He was also taught how to bath himself. I'm happy because now I don't give him a bath. The teachers give them the support to learn these activities. The children in the mainstream school support those in the special unit. The children from mainstream classes were assigned to look after the pupils with special needs. At school, I feel he is given responsibility to take

care of the other disabled children and this is good for him. He grows in responsibility" (CG7).

However, caregivers expressed challenges with the nature of power relations played out in educational institutions, which they felt created the possibility of their children with ID being exploited owing to gullibility. Because of the necessity of having their children in school even with few facilities available, the caregivers opted to remain silent about the situation.

> "Parents were asked by the teacher to stop visiting the children in school but we can see that things are not going well. We remain silent because we need our children to be in school. The situation in schools needs to improve" (CG5).

People with ID liked school but felt that they did not make any educational progress (PWID 1). Caregivers supposed that the situation was likely due to the poor capacity of teachers to work with people with ID (CG8). They also observed that schools lacked supervision of the quality of education people with ID were getting and its impact on their lives, hence the poor outcomes.

> "Situations in special schools are not checked especially in looking at the quality of education. I feel that there needs to be supervision and something happening because parents are desperate and angry" (CG6).

4.6.3 Individualised supports for individuals with intellectual disability

With poor educational outcomes, people with ID did not successfully progress into vocational training and careers. The situation may also be attributed to a lack of individualised supports. Families managed to empower their members in alternative ways, such as providing them with small pieces of land to manage and receive an income from crops they grew (CG3). This was only possible for the few families who had land. They also felt that the possibility for individuals with ID to work in the community was hindered by the general belief that people with ID could not work, for which they felt the need for advocacy.

> "You can even work with the village elder. I think you are not asking for something unreasonable. This is a common thing and should be possible. It would help people change their ideas about people with intellectual disability" (CG in FGD 1).

The necessity for individualised support was expressed over concerns about exploitation of individuals with ID when left on their own to fend for themselves.

> "They get exploited by employers who give them a lot of work and will not give them a pay equivalent to the work. Or sometimes, as long as you buy them something to eat, then they don't even ask for pay. I have seen neighbours who buy mandazi worth Ksh 10 and give a young man with intellectual disability cows to graze the whole day" (CG in FGD 2).

4.6.4 Supports for people with multiple impairments

Caregivers expressed having challenges with a lack of rehabilitation services, respite care and unavailability of adaptive devices for individuals with profound ID and multiple impairments. In some circumstances, families were forced to make choices between taking their children to school at the expense of other needed services or vice versa. They cited the need for holistic approaches to rehabilitation where education was available together with services such as physiotherapy or occupational therapy in schools which the disabled members needed.

> "When my daughter joined school, I stopped taking her for therapy. She has deteriorated because in school she is placed on the wheelchair the whole day and they do not receive such services as therapy. I think in school they care for other issues but not therapy needs. She has developed contractures and it is now painful to stretch her" (CG5).

Adaptive devices such as wheelchairs were difficult to acquire as well as expensive and so difficult for families to afford. They also raised concerns that when adaptive devices were prescribed and provided for use by people with ID in schools, teachers and support workers in school did not follow-up on proper management of the intended device use or the devices ended up not been used at all which led to physical deterioration of disabled members.

> "It's not easy to get a wheelchair because they are not available and when you get one it is very costly. It is painful for us to see that when we do our best to acquire the devices they are not put into good use in school. We bought a corset for our daughter to correct her back but it was only used for only one year at school. It still is very new and was very expensive to buy but it was useless to spend so much money for nothing. She has overgrown and can no longer use it" (CG5).

A lack of adaptive devices was also viewed as a hindrance to accessing places of interest and limited social interaction of individuals with multiple impairments.

> "If your child requires a wheelchair to move and it is not available, how do you take them to school? It's difficult to get the things the child needs to be able to be in school. They also lack company because they remain in one place all their life" (CG6).

The challenge of managing individuals with multiple and profound impairments at home was raised by caregivers. Caregivers expressed a lack of ability to handle or teach the individuals some skills. The need to have support services by agencies (respite care) was suggested as an alternative that would assure families of protection and good care to meet the needs of their disabled members. "Having a safe place that is nearby where I can leave my child during the day when I go to work could make my life easier" (CG1).

> "Support for children who do not know how to feed, who lack some level of self-awareness, those who do not know whether they are clean or not is quite demanding. They need someone who understands them and helps them to achieve some goals as other people" (CG6).

4.6.5 Rights of people with intellectual disability

People with ID stressed the need to be treated the same as other people and with respect. They felt that increased focus on the impairments led to magnification of disability.

> "It's very important to listen to us and to view us as important people" (PWID2).

> "I would like that people take my opinions seriously regardless of my disability" (PWID4).

Some of them felt constrained within the home and were not allowed the same independence and autonomy as their siblings.

> "I live with my grandmother but would like to move away from home like my elder brothers" (PWID5).

4.6.6 Government support

Caregivers felt that the government lacked clear guidelines of policy and practice towards support for people with ID. There was poor arrangement of services, the dissemination of information for people with ID was not consistent, and there were no clear structures for information to reach families.

> "We have challenges because my mother is old. Whenever issues about disability are being discussed she may not know about it or maybe she did not attend the meeting and important issues were discussed. There are no other ways of helping us know what happened in the meeting. We only came to know about registration of disabled people recently when others had already registered. We rely on the goodwill of other parents to help us know important issues" (PWID1).

Although government provided some money (cash transfers) to support families with disabled members, caregivers reported inconsistency with these transfers, as well as how meagre the amount was compared to the needs of the disabled member.

> "Although I do receive Ksh 2000 (*approx. 20 dollars*) from the government, the amount is negligible compared to the needs of my child. There also lacks consistency in the money given. It's possible to receive it just once to three times a year" (CG1).

Due to a lack of clear structures, caregivers felt that they often risked exploitation by individuals who collected and used information regarding disabled people for their personal gains. As a result, they were cautious about getting involved in initiatives that posed as disability service providers in the community because they couldn't tell when people were genuine or not.

> "We have once been told to register as people with disability, but nothing happened after that. We feel exploited by people who keep registering us, asking for pictures and promise support which never materialises" (CG3).

4.7 Community supports

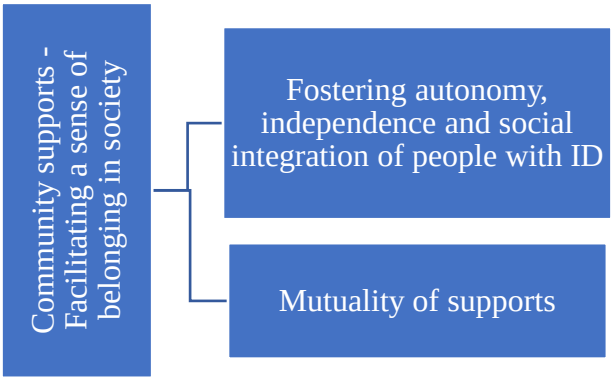


Figure 12: Themes and sub-themes of community supports

In this study, a sense of belonging to the larger society and cultural beliefs influenced family life. Community supports were viewed as integral to individuals with ID to feel a part of society, grow in their independence, and form relationships. Characteristics of the African ethic of *ubuntu*, where human beings are viewed as dependent on each other for progress, were expressed through sharing in the community and supports for people with ID by service providers in collaboration with the families. These aspects are discussed using excerpts from the interviews.

4.7.1 Fostering autonomy, independence and social integration of People with ID

Social integration was described as being possible when community members collaborated in support of individuals with ID and with service providers in the community. According to caregivers, successful integration happened when community members were not overly preoccupied with the presence of ID but rather focused on the capacities one had.

> "Yes, my grandson even takes himself to hospital when sick. I just write my telephone number on the hospital booklet and tell him to tell the doctor to call me if need be. He takes himself to hospital and is treated well. He goes to church even as far as 4 km away and will return home safely because the road is direct and he knows the area well" (CG3).

Some families in Nyahururu and Kinamba felt that, to a certain extent, members with ID were socially integrated in society. This was described people with ID being involved in community activities together with their peers. Caregivers expressed satisfaction with it because it gave a sense of belonging to individuals with ID.

> "When people get used to them, they view them as part of them. People in our community don't view them differently. They see them as normal people even though they behave differently. They will know they have an intellectual disability and even though they say something that they did not expect, they understand them. He goes for community celebrations such as after boys in the community are initiated into adulthood. He will go for the ceremony because he is also counted among the adult young men" (CG3).

4.7.2 Mutuality of supports

Mutual relationships with community members were described as supportive by caregivers. Some of such initiatives included volunteering to offer support or provide for needs that families were unable to meet.

> "The teacher has been very kind to me. She committed my neighbour to help me care for this child with a disability. They follow all issues about medication and when my son is hungry, she gives him food" (CG2).

In Kinamba, to mitigate the effects of poor material conditions, community members in one village would pool resources together and provide each family with sufficient food on a monthly basis. It ensured good nutrition and that at least children were given daily meals. Such interventions also kept the community united.

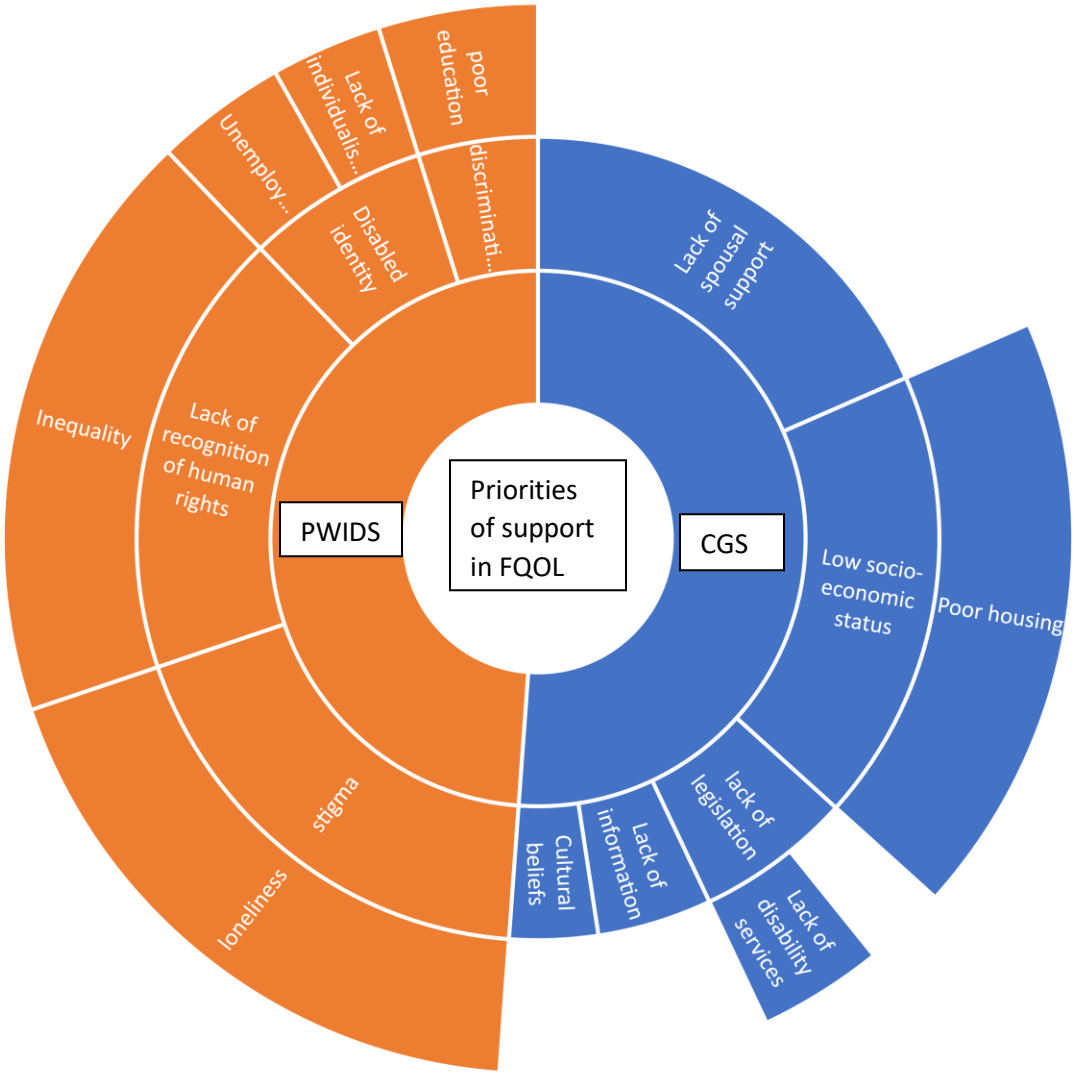
> "Being in the group helps us support each other and we believe it keeps us united. We don't compete about who is richer and hence we ensure that families at least afford basic items like food. In this way, children in the neighbourhood don't feel that they cannot afford good meals in their homes" (CG4).

In summary, satisfaction with FQOL for PWIDs in this study setting were determined by safety, family supports and participation. For caregivers, satisfaction was drawn from community supports and cultural traditions. The influence of culture was seen in how they developed

resilience from the point of view of an ethics of care drawn from cultural ethical provisions of ubuntu.

Figure 13 below presents the priorities for supports drawn from the factors that detracted from FQOL. For PWIDS, these involved a disabled identity, inequality, poor education and vocational training, unemployment, lack of recognition of human rights, stigma and loneliness. For caregivers, priorities for supports revolved around low socio-economic status, lack of disability services, lack of spousal support, lack of information and guidelines for support systems.

Figure 13: Summary of FQOL findings in Laikipia County



5 CHAPTER FIVE: DISCUSSION

5.1 Introduction

The purpose of this study was to determine the FQOL of people with ID and their families in Kenya with an aim of identifying their support needs. The research questions were:

1. What is the family quality of life as perceived by people with intellectual disability and their parents/caregivers in Nyahururu?
2. What are the perceived support needs of people with intellectual disability and their parents/caregivers in Nyahururu?

In this chapter, I will discuss the findings about what constitutes FQOL from the perspective of individuals with ID and caregivers from Laikipia County in Kenya. Caregivers in this study are family members who are responsible for caring for the individual with ID. As per global findings, FQOL for people with ID consists of family interaction, parenting, physical/material wellbeing, emotional wellbeing, disability-related supports and, in addition, community supports for the Kenyan context. To the best of my knowledge, this is the first undertaking a study of the FQOL of individuals with ID in Kenya with the aim of identifying their support needs.

5.2 Family quality of life of people with intellectual disability in Kenya

Following the analysis in Chapter 4, this chapter discusses how the three main factors: poverty, rights of people with ID and community integration influence the FQOL of people with ID and caregivers in Nyahururu, Kenya. The discussion about poverty raises the awareness of how politics of poverty reveal power dynamics that can hinder or deflect satisfaction with FQOL in materially deprived contexts. Additionally, dynamics of gender disparity and low-income levels which become a vicious cycle contributing to material hardships experienced by the family are highlighted. The issues of concern discussed here regarding the rights of people with ID in Nyahururu revolve around education, work, accessibility to services and individualized supports. Finally, community integration is presented following the great yearning for a sense of belonging presented. The factors that hinder it such as community attitudes, stigma, cultural practices and beliefs and those that enhance it such as values of ubuntu are discussed.

5.3 Poverty

The majority of caregivers in this study argued that material hardships rendered them unable to provide for the important needs of people with ID. Being dependent on casual work meant they had inconsistent and poorly paid sources of income (*approx. US$ 2 per day*). In the literature, financial stability has been shown to be essential for families of people with ID so that they can manage care needs appropriately such as health needs, having personal assistants, and other services the individual might need (Arnold, Heller & Kramer, 2012; McNally & Mannan, 2013). Caregivers in the study felt that although material wellbeing was far from meeting their daily needs, it was not isolated to families of people with ID.

5.3.1 A cross-cutting issue

Despite the fact that various needs a member with ID could have economic ramifications on the family, disability activists argue that magnifying poverty as an important characteristic of families with people who have ID is a misconception that sustains oppression and discriminative practices towards them (Thomas, 2002). Viewed as poor people, such families risk being viewed as people who are at the mercy of those who help them. The power relations involved in the politics of poverty deprive families of the power to believe in themselves and to claim their rightful place in society (Berghs, Dos & Zingale, 2011). Such imbalance of power leads these families to submit to those who help them despite having a full understanding of the family's experiences and needs. The family's needs therefore go undiscovered and unmet when the voices of family members cannot be heard. To discover the needs of families with people with ID, practical involvement of family members is essential.

An example of how the balance of power worked is seen in Kinamba where community members pooled resources together to manage feeding needs of families to mitigate the effects of poverty. The culture of sharing resources was born out of the need to have each person's basic needs met for the greater wellbeing of everyone. Such initiatives borrow from a culture of *ubuntu*, which worked for families. In this way, the community had a way of contributing to a family's material needs in a way that did not project poverty as a problem solely affecting families that had people with ID. The example of the community in Kinamba, which stems from a belief in the culture of sharing resources, enriches the understanding of the value of strengthening good cultural practices and beliefs for the good of not only families of people with ID but as a sustainable support for families of people with ID by society generally.

5.3.2 Income of caregivers and gender disparity

The income of families of people with ID has been shown to be influenced by the ability of caregivers to go to work (IASSIDD, 2013; Robert, Leblanc & Boyer, 2015; Brown, 2017). Caregivers needed to remain home to look after individuals with ID with high dependent needs. In most cases, mothers remained at home, as caregiving in the study's context was largely regarded a woman's role. The various responsibilities for the family and care for the disabled member were therefore assumed by mothers. Traditional practices in this sense seemed to be more oppressive of women than supportive. Women seemed to have internalised the oppression without expectations to receive support from their husbands. This made caregiving a gender issue because of the assumptions of the role in parenting in Kenya. Scott (2010) observed that this led to economic exclusion of women. Families also became socio-economically disadvantaged as they mostly relied on mothers who traditionally were perceived to assume the caregivers' role. The impact of caregiving on women in Kenya needs to be studied further for better articulation of required supports for women and their families.

5.4 Rights of people with ID

Issues of rights of people with ID were a big concern to families and people with ID around education, work, access to environments and having individualized supports for people with ID.

5.4.1 Education of people with ID – A systemic discrimination

Education has been seen to improve the livelihood of people with ID. The possibility of gainful educational ventures for people with ID has been facilitated through individualised supports which are dependent on personal characteristics and contextual factors (Robertson et al., 2007). The value of education in this study's context could not be overstated. Education was viewed as a very important factor contributing to the wellbeing of members in society, a view which was enhanced by the belief that, with education, life improved and poverty lessened. This was because the community believed that education offered opportunities for self-development and future engagement.

However, the high cost of education in schools for people with disability revealed a form of systemic discrimination, where individuals with ID had to attend special schools which were not free, as it was for their peers in mainstream schools. Additionally, such schools were mainly far away from home. As these were boarding schools, parents had to provide for the upkeep and personal effects of their children, placing huge economic burdens on the already economically

disadvantaged families. Families plunged into further vulnerability when affected by economic crises, such as trying to salvage the situation by selling the little property they had.

People with ID in this study reported receiving very poor education. The quality of education provided to members with ID in Kenya was challenged on the basis that it lacked structure (curriculum) and systems of support. None of the participants in this study had gained tangible vocational skills they could rely on for career development. In school, emphasis was put on hygiene issues and skills of daily living.

Caregivers also expressed displeasure at being locked out of the educational discourse of their children, citing power challenges with educational institutions. Desperate to improve livelihoods of people with ID, caregivers fell prey to exploitation by community members who disguised themselves as disability support services providers to source funding from donors, only to benefit themselves economically.

5.4.2 Work for people with ID

Work has been viewed as an expression of dignity, an opportunity for self-determination, autonomy, social interaction and increased independence for people with ID (Balandin, Llewellyn, Dew, Ballin & Schneider, 2006). Filmer (2008) notes that there is a vicious cycle caused by low school attainment for people with disabilities in low-income countries, leading to poor economic and work outcomes. Consistent with findings from a study in Nairobi, people with ID hardly made it to the job market (Musima, 2014).

Owing to poor educational outcomes, the alternative for people with ID was to turn to odd jobs which other community members did not like. For example, some members with ID reported to be preoccupied with grazing sheep, goats or cows as vocational and economic empowerment. Such empowerment interventions were challenged on the basis that people with ID got treated as a homogenous group lacking variety and therefore that these interventions were discriminatory in nature. The interventions were also seen to sustain prejudice against people with ID as being seen as unable to work. Being not able to work and engage with other members of society also contributed to social exclusion. People with ID therefore relied entirely on their families and well-wishers for their financial needs. Their right to self-determination, choice and autonomy were therefore grossly curtailed. Reid-Cunningham (2009) notes that such experiences result in people with ID systemically being socioeconomically disadvantaged.

In a bid to bridge the gap of such inequalities, rights-based approaches have been preferred as pre-requisites to achieving meaningful employment for people with ID (Lysaght, Ouellette-Kuntz & Lin, 2012). The constitution of Kenya recognises the Kenyan Disability Act (developed in 2003 and reviewed in 2015) which provides for the rights of people with disabilities. Article 54, section 18 part 3, provides special considerations for people with ID with regards to developing curricula that provide formal education, skills development and opportunities for self-reliance. What becomes apparent is that special considerations for reasonable accommodations only recognise the rights of people with physical impairments. Those of people with ID who require supports beyond physical adjustments to integrate well into society are not considered. This requires an adjustment of legislation and the development of policies and guidelines to consider supports for people with ID who already have challenges with education and employment due to a lack of supports in Kenya. Article 17 of the UNCRPD, which Kenya has ratified, states that every individual with disability has the right to be respected for their physical and mental integrity on an equal basis with others.

5.4.3 Access to services

Accessibility of environments, communication, safety and security are markers for decent livelihood which people with disability have lobbied for in many countries. They are enshrined in the UNCRPD (2006) and reported as essential in the World Report on Disability (WHO, 2011). In this study, accessibility had two different dimensions: Location and availability of devices.

1) Location

Caregivers and individuals with ID in this study were concerned with having decent housing and proximity to essential services such as hospitals, schools, shops and churches. Decent housing was expressed as a factor that would convey the message that members with ID have human dignity and need to be treated as such. Proximity to the services required by people with ID also made it easier for families to support their members in accessing the services. This influenced family decisions about where to live. Some of the families moved to urban settings to easily access these services as well as to find casual jobs for the caregivers. The decision did not always achieve the desire for decent housing as this came at a higher cost than families could afford. Moving into Nyahururu, the main town, forced them to live in informal settings. The risk

involved in the informal settings was to the security and safety of people with ID. In order to change the public perception of people with ID, families expressed the need to be supported to afford decent housing and considerations of having services in close proximity, especially in rural areas where it was relatively safe for people with ID.

2) Availability of devices

For caregivers who had an individual with multiple impairments, the lack of adaptive assistive devices was cited as a major challenge. Scarcity of commodities and the costly nature of adaptive devices such as wheelchairs was further cited. Disability activists have seen this as a systemic oppression and discrimination of individuals with disability that serves to exclude them in society (Thomas, 2002). Accessibility for multiply impaired individuals in this study was greatly hindered by the factor of cost and availability. Caregivers cited physical deterioration which further increased impairment and limited the disabled member's functioning. Caregivers also noted that a lack of such devices affected the social interaction of the people who relied on them for mobility.

5.4.4 The need for individualized supports for people with ID

The International Classification of Functioning, Disability and Health (ICF) recognises the role played by personal and contextual factors in hindering or promoting participation and functioning (WHO, 2001). Individuals with permanent impairments are therefore disadvantaged when viewed as not capable of participation where even simple interventions such as helping them cross the road would effectively enhance their wellbeing. In this study, poor outcomes in education and work was related to the lack of provision of individualised supports for people with ID in the spheres of life that they required it. A lack of these supports contributed to low attainment in education, feelings of inadequacy with employment, low participation in everyday activities and low social interaction. Personalised supports for individuals with ID have been highlighted in several studies as enhancing functioning at home, school and work (Luckasson et al., 2002; Salvador-Carulla & Saxena, 2009; Thompson et al., 2009; Harris, 2013; Tassé, Luckasson & Nygren, 2013; Bertelli et al., 2015).

The lack of provision of individualized supports seem to emanate from people with ID being viewed from a medical model perspective in Kenya. The medical model perspective leaves most interventions at the level of addressing the impairment rather than seeking to reduce adaptive

limitations through providing supports (Luckasson et al., 2002). When interventions failed, blame was put on individual limitations, therefore admonishing the individual with ID. Providing individualized supports was seen as a necessity to bridge the gap of inequality that exists between people with ID and the general population. Supports for adults with ID have ranged from support for practical things, work, independent living and disability-related services, which was a similar finding in this study (White & Hastings, 2004; Davis & Gavidia-Payne, 2009; Hole, Stainton & Wilson, 2013). The costs of having individualized supports for people with ID however would be a further financial burden on families. The need to be supported to manage expenses related to providing supports for their members with ID was highly recommended.

5.4.5 Dealing with future uncertainties

Consistent with findings from two studies, as the needs of the individual with ID kept changing with life transitions, families would worry about the future, supports and finances (McConkey, McConaghie, Barr & Roberts, 2006; Leonard et al., 2016). The ageing of caregivers and a lack of information regarding ID were cited as challenges caregivers faced when their adult disabled family members transitioned into adulthood. As in other studies, families had real uncertainties regarding the future of their members, which was associated with a lack of organised support services as well as insufficient resources for the family to access the services their members needed (Gona et al., 2011; IASSIDD, 2013). A lack of systems that coordinated services for people with ID contributed to the challenges the families faced with disabled members. In a bid to secure certainty for the future of members with ID, families fell prey to exploitation by 'disability actors'. This highlighted the need for family rights perspectives and the state provision of support services for families in Kenya that needed to be put in place.

As the WHO Atlas ID observed, the haphazard deployment of government services for people with ID in different programmes contributes to lack of harmony and results in little or no attention to the discourse (Mercier et al., 2008). The absence of the ID agenda in governments contributes to a devaluation of people with ID in society with eventual inequality, stigma and discrimination. This further disadvantages people with ID who, because of the nature of impairments, lack the social capital to mobilise government into considering their needs (Adnams, 2010; WHO, 2011). Advocating for family support services in Kenya would be an indication of the commitment to bridging the disparity in the livelihoods faced by people with ID and a propagation of their inherent rights. However, according to people with ID, the provision

of services and advocacy for their rights are not enough to bridge the gap of inequality. A sense of belonging fostered by relationships needs to be cultivated (Asselt-Goverts et al., 2015). Caregivers in this study reiterated the need to deal with community attitudes towards disability more than provision of services. Changes in attitude would change a lot of things, including provision of the services, how they were provided, and the reason for the services.

5.5 Community integration

Participants in this study expressed how being integrated in the community would serve as a strength to their family quality of life. The ICF (WHO, 2001) and the World Report on Disability (WHO, 2011) highlight how attitudes and cultural beliefs contribute to the experience of disability. In this study, cultural and current practices, traditional beliefs, intersections in disability served to further alienate people with ID and family members from mainstream society. The negative perceptions and attitudes towards people with ID seemed to be based on a poor understanding of ID. On the other hand, participants in this study viewed some cultural values as a strength to FQOL reiterating the values of Ubuntu. Harnessing the benefits of ubuntu would shape the ethics surrounding care that people with ID require and have been discussed in this section.

5.5.1 Stigma, discrimination and isolation

In most African studies on disability, stigma and isolation emanate from the belief that being disabled is a sign of having been punished by God or of a misfortune in the family (Njenga, 2009; Berghs, Dos & Zingale, 2011; Gona et al., 2011; Aldersey et al., 2012). Gona et al. (2011) observes that in the Coastal region of Kenya, the oppression of people with ID and their families was perpetuated by cultural beliefs and practices. A number of examples of stigma, discrimination and isolation arose in this study. Community members were reported to hold the view that ID was a family misfortune or caused by witchcraft or a curse. This led to stigmatising attitudes such as being laughed at, verbal abuse, pity, and people keeping their distance in public spaces, staring, or crying at seeing a person with disability. Caregivers noted how reactions of pity or awe were an expressed of rejection by society. Such responses revealed a negative conceptualisation of ID which was felt to discriminate and sustain inequality among people with ID and their families.

Stigma around disability has also been seen to cause exclusion of families, caregivers and disabled members in society (Gona et al., 2011; Zuurmond et al., 2016). In Nyahururu and Kinamba, caregivers were blamed by extended family members for having disabled children and were left to provide the care needs alone. In a culture where being part of the larger society gives a sense of belonging, caregivers felt excluded and had low self-esteem. As parents, they bore the blame of having caused the disability which led to even close relatives distancing themselves from families.

5.5.2 Intersections in intellectual disability

Intersections of age, gender, culture and tradition had an impact on individuals with ID. Rites of passage such as circumcision marked a change of status and transition into adulthood for young men. Societal expectations required young men to assume autonomy and independence in thinking, organising themselves and carrying out duties after changing their status to young adults. A number of factors surrounded the issue of intersectionality and individuals with ID. First was the belief that the individuals with ID would continue to require support, including living in the same family house. This was believed to be a taboo once initiated into adulthood and caused conflict in some families. Secondly, there was a dilemma regarding how to provide support and cultivate independence for the member while living outside the house contrary to societal norms after status change into adulthood. Thirdly, failing to go through the rite of passage would be reason to be stigmatised and discriminated, which would have psychological effects on the person with ID as they would continue to be viewed and regarded by peers and society as a 'child', even in adulthood. Under such circumstances, the individual would suffer double discrimination and exclusion, both within the family and in society. Age and gender therefore were important intersectional discourses to have in mind while dealing with matters of individuals with ID in Kenya. The reality of how cultural practices affect the lives of people with ID opens a conversation that needs to be addressed culturally since culture does provide identity to people. Caregivers sought to be helped with finding appropriate interventions to the culturally imposed dilemmas.

5.5.3 Ubuntu- A valued cultural ethic

One notable cultural strength that families symbolized was the African ethics of *Ubuntu*. *Ubuntu* is a cultural traditional ethic upholding the belief that humanity is interconnected and interdependent (Broodryk, 2007). It is observed in cultural practices characterised by being

welcoming, hospitable, generous, warm and willing to share in happy and difficult moments of life (Phillips, 2007). Such practices were symbolized in this study, such as the communal sharing of resources which helped families in dire economic constraints. Caregivers lauded such initiatives which cultivated a sense of belonging, especially as they were not being specifically targeted for having a member with disability, which had the connotation of being different.

Elsewhere in Mailoinya, community supports could be seen in the way people with ID got involved in communal activities. This portrayed the acceptance of people with ID, contradicting notions of a disabled identity. Through community supports, the level of autonomy and independence for individuals with ID increased. This shows that a community with positive regard for people with ID can facilitate a positive self-esteem and increase self-representation. In a sense, a community that upholds a consciousness of the rights of people with ID acts spontaneously in providing supports, which also increases people with ID's safety (WHO, 2001). This is cultivated by an attitude of concern for the welfare of people with ID as evidenced by supports. Community supports can increase the sense of belonging and social integration by way of having friends and participation of individuals with ID. In the Kenyan setting, where systems of ID supports are less developed, communities could use their strength of cultural traditions such as *ubuntu* to create a sense of belonging in people with ID.

5.5.4 Conceptualisations around ethics of care

Ethics of care regards relationships and interdependence as being at the core of human relationships. An ethics of care that views services for people with ID not as a burden of care but as a necessary responsibility to improve the lives of a population that matters has been advocated for (Carlson & Kittay, 2009). In this study, it was evident that families viewed their disabled members different from the way community members viewed disability. People with ID expressed close bonds with family members who they viewed as important anchors for support and relationships. Prejudice about disability seemed not to be an issue affecting family members as much as it did community members. The finding is consistent with a Tanzanian study where families were also seen to be more accepting of their disabled members (McNally & Mannan, 2013). Family members were more accepting of family members with ID which possibly came from having an experience that taught them a different reality to traditional beliefs and culture that informed other societal members otherwise about ID.

In one of the FGDs, one caregiver expressed that having an impairment mirrored the human condition of being vulnerable and being limited during one's life course, which was not an isolated experience of people with ID but for everyone. Attributing impairment and vulnerability only to disabled members served only to perpetuate oppressive and discriminative practices. The psychoanalysis belying this perception has been discussed by Watermeyer (2000) who argues it as a subconscious response to the need for human beings to feel in control of their lives and the fear of uncertainty. Disability is thought to awaken the subconscious reaction to realities that people don't want to face such as weakness, vulnerability or death. These reactions have contributed to the negative perceptions of disability which has been seen as a vulnerability over time. In a bid to flee the reality of weakness and vulnerability that human beings experience from time to time, bodily limitations (often perceived as "disability") provokes this reality in those who do not have impairments. In a bid to create an illusion that weakness and vulnerability can be avoided, having a body without an impairment is 'idealised' while disability is shunned and viewed as a 'bad difference' (Barnes, 2014).

Stigma, discrimination, inequality and violence follow from this perception as was seen in this study where people with ID were devalued by community members through experiences such as exploitation at work or being given odd jobs to do. The same perception seemed to be the influence behind a lack of social networks for individuals with ID, most of whom did not have friends as well as leisure activities to participate in.

It seems that the acceptance of caregivers of the conditions of vulnerability for the disabled family members could be attributed to ethics of care embedded in cultural beliefs and practices of *ubuntu*. It could also be attributed to the situation of poverty that made people internalise humility, appreciating what is received with gratitude and not as a right. It was the observation of caregivers that in caring, people with ID contributed towards building up cohesive societies in an indirect way. This observation has been reiterated by Carlson and Kittay (2009). The caregivers observed that they had transformational experiences in actions such as gratitude they received from their disabled members. Love and trust brought the best out of the people with ID, which they felt shaped the way they related with others in an intentional way. Ethical care was therefore perceived as important work which helped the individuals with ID have stability as well as built wholeness in the community. Caregivers, however, remained conscious of the fact that there

were limitations experienced by their disabled members that required specific supports to improve their quality of life.

According to Kittay (2006), care is a form of justice. Recognising that anyone could have an impairment any time, affording care in a respectful and dignified way was therefore seen as important. People with ID felt that care and support provided them with dignity while caregivers felt that caregiving impacted positively on their wellbeing. Ethics of care promoted humane values, which had moral underpinnings that helped people relate with each other, respecting their dignity. Caregivers argued that caregiving offered them an opportunity to strengthen moral values of respect for other human beings and their dignity.

For example, by caring they became caring persons. The difference it made was that caregivers learnt to be more open to differences in culture and ethnicity in their regions, which was mirrored in the relationships they had with the disabled family members. As such, while individuals with ID depended on the family for care and support, caregivers felt they profited from the relationships in return. This finding is also consistent with Lindemann's (2009), regarding the capacity of care to uphold one's humanness. Such perspectives have been seen to diminish the negative view of dependence (Kittay 2006; Gouws & Van Zyl, 2014). As such, the belief in the value of care strengthened caregiver's capacity to be resilient. The values created by mutual relationships were viewed positively as they shaped their conscience, helping them to regard other members of society with respect irrespective of class, ability, ethnicity or what they stood for.

6 CHAPTER 6: RECOMMENDATIONS

6.1 Introduction

In this chapter, I will be presenting the recommendations for supports as expressed by caregivers and individuals with ID informed by the FQOL themes that emerged from the study. The main themes discussed in this chapter are disability-related supports and caregiver to caregiver support. Narratives around ID need to come into the limelight to inform cultural beliefs and general practices to support people with ID and their families, in order to bridge the gap of inequality that currently exists in Kenya.

6.2 Disability-related supports

Disability-related supports in this section are discussed as the systems and services that people with ID and their families require to enable their functioning and enhance their wellbeing. These include individualised supports for people with ID, information and disability services, policies and guidelines on family support services, legislation, welfare and resources for family support services, and respite care.

6.2.1 Individualised supports for people with intellectual disability

Supports and care are interrelated. Emphasising the need for supports in conceptual, practical and adaptive skills for people with ID in Kenya is essential if they are to find their place in society. Intellectual disability and supports need to be reconceptualised in Kenya if people with ID are to make any progress in individual or FQOL. An increased awareness of the construct of ID needs to be advocated for to inform professional practices and traditional beliefs in Kenya. Providing the community with different perspectives of people with ID, such as being able to live, work and integrate into society, would increase people with ID's acceptance and make life easier for them. Changing perceptions of stakeholders from viewing people with ID from a deficit-based medical model that sees them as unable to learn and develop skills requires advocacy.

Without the realisation of how individualised supports can improve cognitive, adaptive and practical limitations, notions that the family have to handle the issue of disability alone will remain. The desire of families and people with ID to belong to a community will be dashed as the invincible line continues to depict ID as 'their' (the family's) problem rather than in the epistemological and ontological construction of ID in Kenya. Community attitudes and

traditional beliefs also require a reconceptualization of ID so that they can better provide supports and have an open predisposition to disability. Cultural beliefs about disability posed a systemic problem, as culture is passed on from generation to generation. As a powerful tool that shapes societal attitudes, there is a need to positively portray individuals with ID and welcome their difference as a form of diversity. *Ubuntu* and ethics of care offer positive perceptions towards notions of support and acknowledging that human beings are interdependent on each other. Such narratives promote a sense of belonging to people with ID and ease the burden of care for caregivers in fulfilling their roles without prejudice.

6.2.2 Information regarding intellectual disability

Information around ID was likely to reduce stigma and discrimination which would make it easier to have friends, develop a range of leisure activities, and work. The World Report on Disability (WHO, 2011) also makes recommendations to improve information on disability to reduce the disability experience. Some of the required interventions may not necessarily be within reach for the family and they also need to be addressed at different levels, such as policy guidelines. For example, information regarding disability services in Kenya is mainly coordinated from Nairobi, making it very difficult to receive information in the rural areas, such as this study's context. Disability services in Kenya need to be decentralised to grassroots levels in order to reach families.

6.2.3 Policy development for family support services for people with intellectual disability

Policies and guidelines to ensure family support services for people with ID need to be put in place. The UNCRPD (2006) forms a good basis for development of such policies, as it incorporates an internationally agreed upon rights framework for people with disabilities. Additionally, some of the contextual factors have been highlighted in this study such as the influence of culture, with a specific emphasis on *ubuntu*, which could serve the interests of people with disability in a positive manner. Government policy on ID will inform well-coordinated family support services to offer information and guidelines to families and service providers. This will ensure that information and services reach families in a timely manner and that majority of families receive useful information.

Given the unequal attention that issues of ID receive, recommendations would be to have specific programmes that deal with particular issues of ID in government. One of the important area would be to look into education of people with ID, develop suitable curriculums and

appropriate teaching services. Another area would be to find ways of creating work opportunities for people with ID with provisions of necessary supports. This includes affirmative action in education, vocational training, legislation and policy development, with specific interventions for people with ID both within the community and nationally. Such measures would ensure that the educational and vocational challenges raised in this study are addressed together with other needs such as safety, work and the need for respite for families. It would also address the issue of scarcity and affordability of adaptive devices for people with multiple impairments to ease the burden of care for families with disabled members who need them. Advocating for this change will help society be more willing to support people with ID and not denigrate them for requiring support (McArthur, 2012).

6.2.4 Legislation

Legislation on ID needs to be developed and implemented where supports are recognised and facilitated. The Kenyan Disability Act (2003) provides for physical accommodations but does not take into cognisance accommodations required by people with ID such as individual supports. All manner of supports that would enhance integration and understanding of people with ID should also be implemented. The Kenyan Disability Act (2003), its revision (2015) and the draft policy should engender issues of ID in a way that would ensure sufficient services with proper funding for effective implementation.

6.2.5 Welfare and Resources

Similar to recommendations of the World Atlas ID report, putting specific ministries in place to address issues of ID in Kenya would ensure the needs are well-resourced, implemented, and monitored, and that progress is being made. This would also ensure that issues of people with ID don't get overshadowed by other development matters.

6.2.6 Respite care

Respite care, as defined in the World Report on Disability (WHO, 2011), is a facility other than the usual place where the person with ID lives, that provides momentary relief to people with ID and caregivers. The need for respite care was expressed in this study due to prolonged caregiving and the related effects of foregoing income, mainly by mothers who were the sole caregivers. Respite was also perceived as a means to offer safety to people with ID. Further, respite would be an opportunity for people with ID to socialise as they often remained secluded in their homes. Some of the proposed services for such facilities included information centres for families,

individualised supports, therapy, education, skills and even employment agencies. The creation of such centres would further curb the fears families would have with exploitation in the community when targeted by people who solicit funds through people with disability. They would also increase levels of certainty for the futures of people with ID addressing the fears of families.

6.3 Caregiver to caregiver support

The need for supporting each other as caregivers was echoed in the FGD. Caregivers noted that they became more aware of their own support needs and those of their members with ID. Such forums were seen as essential supports for them because they were able to share knowledge and support each other. Solomon & Chung (2012) argue that caregivers require supports for a healthy work and family life balance. Supporting caregivers, offers opportunities for them to stay connected, informed and promotes emotional wellbeing. The need for family therapists who understand ID and its discourse is therefore recommended. In this way caregivers would be able to recognise actions they need to take, share circumstances that may be difficult for one to decipher alone and have emotional support. Having caregiver support groups was seen as a way of identifying common challenges in the families and finding ways of addressing them, thereby building up resilience and an ethics of care.

7 CHAPTER 7: CONCLUSION AND LIMITATIONS

7.1 Conclusion

FQOL for families that have individuals with ID is strongly characterised by family interaction, emotional wellbeing, parenting, physical and material conditions, disability-related supports, and, additionally for a setting similar to Kenya, community supports. Community supports, a new theme in this study, are concerned with relationships that enhance the integration of individuals with ID and their families. They bridge the gap identified by people with ID who, despite having support services, have still felt unintegrated into society. Community is also an important factor of support because culture has a big influence on the attitudes that direct societal values. Positive cultural constructions of disability will greatly impact the lives of people with ID and dictate most of the other interventions that could be put in place if there will be any success with FQOL in Kenya. Additionally, addressing poverty will require a further understanding of gender dynamics versus income levels of families and how these impacts outcomes in the lives of people with ID. Society needs a greater understanding of ID to change negative perceptions and to enhance integration. Government requires to implement affirmative action in legislation, education, employment, development of policies and provision of services for people with ID and their families.

This study contributes to baseline information of FQOL of individuals with ID and their families in Laikipia County, a rural setting in Kenya. Further research is recommended to give perspectives from a Kenyan urban setting, since issues affecting families could be different across settings. In addition, gender disparity and how it impacts income in families of people with ID needs to be further researched. This will give a whole perspective to FQOL in Kenya to better inform national policies and support frameworks required to improve the FQOL of people with ID. The study can inform future research on FQOL for people with ID since some FQOL concepts derived from this study are similar to those experienced in other contexts. This study contributes further to the FQOL discussion through the additional concepts of community supports. This is especially necessary with the increased threat to disenfranchisement of people with ID in the face of neoglobalisation which increases their risk of exclusions.

7.2 Limitations

FQOL and support needs in this study should be interpreted while keeping in mind that participants with ID who responded to this study were between 18 and 40 years of age and had mild ID. Caregivers who responded were between 32 and 70 years of age. Participants were all from rural settings in Laikipia County in Kenya. As such, people with ID and their families should not be regarded as a homogenous group in interpreting these findings.

Given the limited time to conduct this study and the nature of the study which included people with ID, not all family members participated and therefore the full picture of FQOL is not comprehensive. Other family members may concur with what caregivers and individuals with ID said regarding the FQOL, but I acknowledge that these are subjective experiences which can only be defined by participants themselves. This can only be confirmed by conducting further studies involving more family members, which was beyond the scope of this study.

8 REFERENCE LIST

Adnams, C. M. (2010). Perspectives of Intellectual Disability in South Africa: Epidemiology, Policy, Services for Children and Adults. *Current Opinion in Psychiatry, 23*(5), 436-440.

Ajuwon, P. M., & Brown, I. (2012). Family Quality of Life in Nigeria. *Journal of Intellectual Disability Research,* 56(1), 61-70. doi:10.1111/j.1365-2788.2011.01487.

Aldersey, H. M., Francis, G. L., Haines, S. J., & Chiu, C. Y. (2017). Family Quality of Life in the Democratic Republic of the Congo. *Journal of Policy and Practice in Intellectual Disabilities,* 14(1), 78-86. doi:10.1111/jppi.12189

APA. (2013). Diagnostic and Statistical Manual of Mental Disorders (DSM-5®): *American Psychiatric Pub*. Available at www.psychiatry.org. Accessed on 6th June 2017.

Arc. (2009). Position statement. Quality of Life. *American Association of Intellectual and Developmental Disorders*. Available at www.thearc.org. Accessed on 20th April 2017.

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support Needs of Siblings of People with Developmental Disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373-382.

Asselt-Goverts, A. v., Embregts, P., & Hendriks, A. (2015). Social Networks of People with Mild Intellectual Disabilities: Characteristics, Satisfaction, Wishes and Quality of Life. *Journal of Intellectual Disability Research,* 59(5), 450-461.

Balandin, S., Llewellyn, G., Dew, A., Ballin, L., & Schneider, J. (2006). Older Disabled Workers' Perceptions of Volunteering. *Disability & society, 21*(7), 677-692.

Barnes, C. (1995). Disability Rights: Rhetoric and Reality in the UK. *Disability & Society, 10*(1), 111-116.

Barnes, C. (1996). Theories of Disability and the Origins of the Oppression of Disabled People in Western Society. *Disability And Society: Emerging Issues And Insights*, 43-60.

Barnes, E. (2014). Valuing disability, causing disability. *Ethics, 125*(1), 88-113.

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Resilience in Family Members of Persons with Autism Spectrum Disorder: A Review of the Literature. *Issues in Mental Health Nursing, 33*(10), 650-656.

Berghs, M., Dos, S., & Zingale, M. (2011). A Comparative Analysis: Everyday Experiences of Disability in Sierra Leone. *Africa Today, 58*(2), 19-40. Doi:10.2979/Africatoday.58.2.19

Bertelli, M., & Brown, I. (2006). Quality of Life for People with Intellectual Disabilities. *Current Opinion in Psychiatry,* 19(5), 508-513. doi:10.1097/01.yco.0000238479.81528.9

Bertelli, M. O., Munir, K., Harris, J., & Salvador-Carulla, L. (2016). "Intellectual Developmental Disorders": Reflections on the International Consensus Document for Redefining "Mental Retardation-Intellectual Disability" In ICD-11. *Advances In Mental Health And Intellectual Disabilities, 10*(1), 36-58. Doi:10.1108/AMHID-10-2015-0050

Bidwell, N. (2010). Ubuntu in the Network: Humanness in Social Capital in Rural Africa. *Interactions,* 17(2), 68-71.

Bramston, P., Chipuer, H., & Pretty, G. (2005). Conceptual Principles of Quality of Life: An Empirical Exploration. *Journal of Intellectual Disability Research*, 49(10), 728-733.

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Boehm, T. L., & Carter, E. W. (2016). A Systematic Review of Informal Relationships Among Parents of Individuals with Intellectual Disability or Autism. *Research and Practice for Persons with Severe Disabilities, 41*(3), 173-190.

Boelsma, F., Caubo-Damen, I., Schippers, A., Dane, M., & Abma, T. A. (2017). Rethinking FQoL: The Dynamic Interplay Between Individual and Family Quality of Life. *Journal of Policy and Practice in Intellectual Disabilities,* 14(1), 31-38.

Broodryk, J. (2007). Understanding South Africa: The Ubuntu way of living.

Brown, I., Anand, S., Fung, W. A., Isaacs, B., & Baum, N. (2003). Family Quality of Life: Canadian Results from an International Study. *Journal of Developmental and Physical Disabilities,* 15(3), 207-230.

Brown, R. I. (2017). Quality Of Life—Challenges to Research, Practice and Policy. *Journal of Policy And Practice In Intellectual Disabilities,* 14(1), 7-14. Doi:10.1111/Jppi.12185

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 6*(1), 11-18. doi:10.1111/j.1741-1130. 2008.00198.x

Brown, R. I., Geider, S., Primrose, A., & Jokinen, N. S. (2011). Family Life and the Impact of Previous and Present Residential and Day Care Support for Children with Major Cognitive and Behavioural Challenges: A Dilemma for Services and Policy. *Journal of Intellectual Disability Research,* 55(9), 904-917. Doi:10.1111/J.1365-2788.2011.01453.X

Buntinx, W. H. E. (2003). The Support of the Handicapped People: Plea for a Handicapped Society. *Hommes et Terres du Nord*(2), 32-38.

Buntinx, W. H. E., & Schalock, R. L. (2010). Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities, 7*(4), 283-294. Doi:10.1111/J.1741-1130.2010.00278.X

Burton-Smith, R., Mcvilly, K. R., Yazbeck, M., Parmenter, T. R., & Tsutsui, T. (2009). Quality of Life of Australian Family Carers: Implications for Research, Policy, and Practice. *Journal of Policy and Practice in Intellectual Disabilities,* 6(3), 189-198. Doi:10.1111/J.1741-1130.2009.00227.X

Carlson, L. (2013). Research ethics and Intellectual Disability: Broadening the Debates. *The Yale Journal of Biology and Medicine, 86*(3), 303.

Carlson, L., & Kittay, E. F. (2009). Introduction: Rethinking Philosophical Presumptions in Light of Cognitive Disability. *Metaphilosophy, 40*(3/4), 307-330.

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'brien, P., Finlay, F., . . . Harrington, G. (2013). Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 119-132.

Chataika, T., Kallon, F., Mji, G., & Maclachlan, M. (2011). Did What? Research Brief: A-PODD in Sierra Leone: *Global Health Press, Dublin*.

Chou, Y. C., Lin, L. C., Chang, A. L., & Schalock, R. L. (2007). The Quality of Life of Family Caregivers of Adults with Intellectual Disabilities in Taiwan. *Journal of Applied Research in Intellectual Disabilities,* 20(3), 200-210. Doi:10.1111/J.1468-3148.2006.00318.X

Chou, Y. C., Tzou, P. Y., Pu, C. Y., Kröger, T., & Lee, W. P. (2008). Respite Care as a Community Care Service: Factors Associated with the Effects on Family Carers of Adults with Intellectual Disability in Taiwan. *Journal of Intellectual and Developmental Disability*, 33(1), 12-21. Doi:10.1080/13668250701832500

Claes, C., Van Hove, G., Vandevelde, S., Van Loon, J., & Schalock, R. (2012). The Influence of Supports Strategies, Environmental Factors, and Client Characteristics on Quality of Life

Related Personal Outcomes. *Research In Developmental Disabilities,* 33(1), 96-103. Doi:10.1016/J.Ridd.2011.08.024

Coons, K. D., & Watson, S. L. (2013). Conducting Research with Individuals who have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research. *Journal on Developmental Disabilities, 19*(2).

Creswell, J. W. (2014). A Concise Introduction to Mixed Methods Research: *Sage Publications*.

Davis, K., & Gavidia-Payne, S. (2009). The Impact of Child, Family, and Professional Support Characteristics on the Quality of Life in Families of Young Children with Disabilities. *Journal of Intellectual and Developmental Disability,* 34(2), 153-162.

Deary, I. J. (2001). Intelligence: A Very Short Introduction: *OUP Oxford*.

Dempsey, I., & Keen, D. (2008). A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability. *Topics in Early Childhood Special Education,* 28(1), 42-52.

Disability Act Kenya. (2003). Available at the Ministry of Labour and Social Services Website, *www.labour.go.ke.* Accessed on 15th May 2017.

Felce, D. J., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E., & Knapp, M. (2008). Outcomes and Costs of Community Living: Semi-Independent Living and Fully Staffed Group Homes. *American Journal on Mental Retardation, 113*(2). doi:10.1352/0895-8017(2008)113[87:

Filmer, D. (2008). Disability, Poverty, and Schooling in Developing Countries: Results From 14 Household Surveys. *The World Bank Economic Review, 22*(1), 141-163.

Foley, K. R., Girdler, S., Downs, J., Jacoby, P., Bourke, J., Lennox, N., . . . Leonard, H. (2014). Relationship Between Family Quality of Life and Day Occupations of Young People with Down Syndrome. *Social Psychiatry And Psychiatric Epidemiology,* 1-11.

Gade, C. B. (2012). What is Ubuntu,? Different Interpretations among South Africans of African Descent. *South African Journal of Philosophy,* 31(3), 484-503.

Grech, S. (2011). Recolonising Debates or Perpetuated Coloniality? Decentring the Spaces of Disability, Development and Community in the Global South. *International Journal Of Inclusive Education, 15*(1), 87-100.

Greenspan, S., & Woods, G. W. (2014). Intellectual Disability as a Disorder of Reasoning and Judgement: The Gradual Move Away From Intelligence Quotient-Ceilings. *Curr Opin Psychiatry,* 27(2), 110-116.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for Children with Disabilities in Kilifi, Kenya: What is the Carer's Experience? *Child Care Health Dev,* 37(2), 175-183.

Gouws, A., & Van Zyl, M. (2014). Feminist Ethics of Care through a Southern Lens. *Care in context: Transnational perspectives. Cape Town: HSRC*.

Harris, J. C. (2013). New Terminology for Mental Retardation in DSM-5 and ICD-11. *Current Opinion In Psychiatry, 26*(3), 260-262.

Heikura, U., Taanila, A., Olsen, P., Hartikainen, A.-L., von Wendt, L., & Järvelin, M.-R. (2003). Temporal Changes in Incidence and Prevalence of Intellectual Disability between two birth cohorts in Northern Finland. *American Journal on Mental Retardation, 108*(1), 19-31.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing Family Outcomes: Psychometric Evaluation of The Beach Center Family Quality of Life Scale. *Journal Of Marriage And Family, 68(4), 1069-1083.*

Holdnack, J. A., Zhou, X., Larrabee, G. J., Millis, S. R., & Salthouse, T. A. (2011). Confirmatory Factor Analysis of the WAIS-IV/WMS-IV. *Assessment*, 18(2), 178-191.

Hole, R. D., Stainton, T., & Wilson, L. (2013). Ageing Adults with Intellectual Disabilities: Self-advocates' and Family Members' Perspectives about the Future. *Australian Social Work*, 66(4), 571-589.

Hughes, M. (2006). Affect, Meaning and Quality of Life. *Social Forces*, 85(2), 611-629.

IASSIDD. (2013). Families Supporting a Child with Intellectual or Developmental Disabilities: The Current State of Knowledge [*Electronic resource*]. Iassidd, 2013.

Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., . . . Wang, M. (2007). The International Family Quality of Life Project: Goals and Description of a Survey Tool. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), 177-185.

Kachaje, R., Dube, K., MacLachlan, M., & Mji, G. (2014). The African Network for Evidence-to-Action on Disability: A Role Player in the Realisation of the UNCRPD in Africa. *African Journal of Disability, 3*(2).

Kasnitz, D., & Shuttleworth, R. P. (2001). Anthropology and Disability Studies. *Semiotics and Dis/Ability: Interrogating Categories of Difference*, 19-41.

Kavanagh, A. M., Krnjacki, L., Aitken, Z., Lamontagne, A. D., Beer, A., Baker, E., & Bentley, R. (2015). Intersections Between Disability, Type of Impairment, Gender and Socio-Economic Disadvantage in a Nationally Representative Sample of 33,101 Working-Aged Australians. *Disability and Health Journal, 8*(2), 191-199. Doi:10.1016/J.Dhjo.2014.08.008

Kenya Society for the Mentally Handicapped. (2014). Available at www.ksmh.org. Accessed on 20th May 2016.

Kim, K.-H., & Turnbull, A. P. (2004). Transition to Adulthood for Students with Severe Intellectual Disabilities: Shifting toward Person-Family Interdependent Planning.

Kittay, E. F. (2006). The Concept of Care Ethics in Biomedicine the Case of Disability *Bioethics In Cultural Contexts* (Pp. 319-339): *Springer Netherlands*.

Kittay, E. F. (2011). The Ethics of Care, Dependence, and Disability. *Ratio Juris, 24*(1), 49-58.

Kroese, S. B., Hussein, H., Clifford, C., & Ahmed, N. (2002). Social Support Networks and Psychological Well-Being of Mothers with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 324-340.

Koros, E. J., & Harrahs, M. (2017). Coping with Down's Syndrome: A Case Study of Parents with Children Suffering from Down's Syndrome in Kenya.

Kuhse, H., Singer, P., & Singer, P. (1985). Should the baby live? *The Problem of Handicapped Infants* (Vol. 138): Oxford University Press Oxford.

Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., . . . Wang, M. (2007). The International Family Quality of Life Project: Goals and Description of a Survey tool. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 177-185.

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., . . . Walsh, P. N. (2005). The Relationship Between Quality of Life and Self-Determination: An International Study. *Journal of Intellectual Disability Research*, 49(10), 740-744.

Laikipia County Assembly Report. (2014). Available at *laikipiaassembly.go.ke/committee-reports/*. Accessed on 12th April 2016.

L'Arche Internationale. (2016). Empowering People with a Disability. *Available at https://www.larche.org*. Accessed on 29th August 2017.

L'Arche Kenya & St Martin Communities. (2014). Beloved, Transforming Encounters.*Paulines Publication Africa.* 15 -45. ISBN 9966-08-873-3

Leonard, H., Foley, K.-R., Pikora, T., Bourke, J., Wong, K., McPherson, L., . . . Downs, J. (2016). Transition to Adulthood for Young People with Intellectual Disability: The Experiences of their Families. *European child & adolescent psychiatry,* 25(12), 1369-1381.

Lindemann, H. (2009). Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia. *Metaphilosophy*, 40(3-4), 416-424.

Luckasson, R., & Schalock, R. L. (2013). Defining and Applying a Functionality Approach to Intellectual Disability. *Journal of Intellectual Disability Research,* 57(7), 657-668.

Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H., Coulter, D. L., Craig, E. M. P., Reeve, A., . . . Spreat, S. (2002). Mental Retardation: Definition, Classification, and Systems of Supports: *American Association on Mental Retardation*.

Lysaght, R., Ouellette-Kuntz, H., & Lin, C.-J. (2012). Untapped Potential: Perspectives on the Employment of People with Intellectual Disability. *Work*, *41*(4), 409-422.

Maina, H. N. (2016). Challenges Facing Transition of Learners with Intellectual Disability from Special Schools to Work in Nakuru County, Kenya. *Doctoral dissertation. School of Education, Kenyatta University*.

Mannan, H. (2014). Development Process in Africa: Poverty, Politics and Indigenous Knowledge. *African Journal of Disability*, 3(2), 1-6.

Markey, U. A. (2000). Forum about Partnerships. *Journal of Positive Behaviour interventions* 2(3) 188 - 192.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies. *Research in Developmental Disabilities*, 32(2), 419-436.

Mcarthur, P. (2012). Carried and Held: Getting Good at Being Helped. *International Journal Of Feminist Approaches to Bioethics, 5*(2), 162-169. Doi:10.2979/Intjfemappbio.5.2.162

McConkey, R., McConaghie, J., Barr, O., & Roberts, P. (2006). Views of Family Carers to the Future Accommodation and Support Needs of their Relatives with Intellectual Disabilities. *Irish Journal of Psychological Medicine,* 23(4), 140-144.

McNally, A., & Mannan, H. (2013). Perceptions of Caring for Children with Disabilities: Experiences from Moshi, Tanzania. *African Journal of Disability, 2*(1), 1-10.

Meral, B. F., Cavkaytar, A., Turnbull, A. P., & Wang, M. (2013). Family Quality of Life of Turkish Families who have Children with Intellectual Disabilities and Autism. *Research and Practice for Persons with Severe Disabilities, 38*(4), 233-246.

Mercier, C., Saxena, S., Lecomte, J., Cumbrera, M. G., & Harnois, G. (2008). WHO Atlas on Global Resources for Persons with Intellectual Disabilities 2007: Key Findings Relevant for Low-and Middle-Income Countries. *Journal Of Policy And Practice In Intellectual Disabilities, 5*(2), 81-88.

Munger, K. M., & Mertens, D. M. (2011). Conducting Research with the Disability Community: A Rights-Based Approach. *New Directions for Adult and Continuing Education, 2011*(132), 23-33.

Murithi, T. (2006). Practical Peacemaking Wisdom from Africa: Reflections on Ubuntu. *The journal of Pan African studies*, 1(4), 25-34.

Musima, P. N. (2014). An Investigation into Factors Influencing Transition Rate of Learners with Intellectual Disability from Vocational Training to Employment in Nairobi County,

Kenya. *Doctoral Dissertation. Available in Kenyatta University Library*. Accessed on 14th September 2017.

Njagi, N. D. (2015). Analysis of Determinants of Access, Retention and Education Achievement of Learners with Intellectual Disabilities in Embu Special School, Embu County, Kenya. *Doctoral dissertation. Kenyatta University.*

Njenga, F. (2009). Perspectives of Intellectual Disability in Africa: Epidemiology and Policy Services for Children and Adults. *Current Opinion in Psychiatry*, 22(5), 457-461.

Nussbaum, B. (2003). Ubuntu: Reflections of a South African on Our Common Humanity. Reflections: *The SoL Journal*, 4(4), 21-26.

Parahoo, K. (2014). Nursing Research: Principles, Process and Issues: *Palgrave Macmillan*.

Park, J., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., Mannan, H., . . . Nelson, L. (2003). Toward Assessing Family Outcomes of Service Delivery: Validation of a Family Quality of Life Survey. *Journal of Intellectual Disability Research*, 47(4-5), 367-384.

Phillips, D. (2011). The Individual and the Social: A Comparative Study of Quality of Life, Social Quality and Human Development Approaches. *The International Journal of Social Quality, 1*(1), 71.

Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family Quality of Life: A Qualitative Inquiry. *Mental Retardation*, 41(5), 313-328.

Reid-Cunningham, A. R. (2009). Anthropological Theories of Disability. *Journal of Human Behavior in the Social Environment, 19*(1), 99-111.

Robert, M., Leblanc, L., & Boyer, T. (2015). When Satisfaction is Not Directly Related to the Support Services Received: Understanding Parents' Varied Experiences with Specialised Services for Children with Developmental Disabilities. *British Journal of Learning Disabilities*, 43(3), 168-177.

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., . . . Knapp, M. (2007). Person-Centred Planning: Factors Associated with Successful Outcomes for People with Intellectual Disabilities. *Journal of Intellectual Disability Research, 51*(3), 232-243.

Rossouw, S & Naude, W. (2007). The Non-Economic Quality of Life on a Sub-National Level in South Africa. *Soc Indie Res* 86:433 - 452. DOI 10.1007/sl 1205-007-9178-3

Salvador-Carulla, L., Leila M. Vaez-Azizi, Cooper, S.A., Martinez-Leal, R., Bertelli, M., Adnams, C., Cooray, S., Deb, S., Akoury-Dirani, L., Girimaji, S.C., Katz, G., Kwok, H., Luckasson, R., Simeonsson, R., Walsh, C., Munir, K & Saxena, S. (2011). Intellectual Developmental Disorders: Towards a New Name, Definition and Framework for "Mental Retardation/Intellectual Disability" in ICD-11. *World Psychiatry, 10*(3), 175-180.

Samuel, P. S., Hobden, K. L., Leroy, B. W., & Lacey, K. K. (2012). Analysing Family Service Needs of Typically Underserved Families in the USA. *J Intellect Disabil Res*, 56(1), 111-128.

Sandy, P., Kgole, J., & Mavundla, T. (2013). Support needs of caregivers: Case studies in South Africa. *International nursing review, 60*(3), 344-350.

Schalock, R. L. (1993). Viewing Quality of Life in the Larger Context. *Australia and New Zealand Journal of Developmental Disabilities*, 18(4), 201-208.

Schalock. (2011). The Evolving Understanding of The Construct of Intellectual Disability. *Journal Of Intellectual And Developmental Disability, 36*(4), 223-233.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., . . . Parmenter, T. (2002). Conceptualization, Measurement and Application of Quality of Life for Persons

with Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6), 457-470.

Schalock, Luckasson, R. A., & Shogren, K. A. (2007). The Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability. *Intellectual And Developmental Disabilities, 45*(2), 116-124.

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., . . . Reeve, A. (2010). Intellectual Disability: Definition, Classification, and Systems of Supports: *ERIC*.

Schertz, M., Karni-Visel, Y., Tamir, A., Genizi, J., & Roth, D. (2016). Family Quality of Life Among Families With a Child Who Has a Severe Neurodevelopmental Disability: Impact of Family and Child Socio-Demographic Factors. *Res Dev Disabil, 53-54*, 95-106.

Scott, E. K. (2010). "I Feel As If I Am The One Who Is Disabled". *Gender & Society, 24*(5), 672-696.

Shakespeare, T. (2006). The Social Model Of Disability. *The Disability Studies Reader, 2*, 197-204.

Shenton, A. K. (2004). Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information, 22*(2), 63-75.

Shogren, K. A., Bradley, V. J., Gomez, S. C., Yeager, M. H., Schalock, R. L., Borthwick-Duffy, S., . . . Wehmeyer, M. L. (2009). Public Policy and the Enhancement of Desired Outcomes for Persons With Intellectual Disability. *Intellectual and Developmental Disabilities*, 47(4), 307-319.

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family process, 51*(2), 250-264.

Sonpal, D., & Kumar, A. (2012). 'Whose Reality Counts?': Notes on Disability, Development and Participation. *Indian Anthropologist*, 71-90.

Stancliffe, R. J., Jones, E., Mansell, J., & Lowe, K. (2008). Active Support: A Critical Review and Commentary. *Journal of Intellectual and Developmental Disability*, 33(3), 196-214.

Sternberg, R. J. (1988). The Triarchic Mind: A New Theory of Human Intelligence: *Viking Pr*.

Strømme, P., & Valvatne, K. (1998). Mental Retardation in Norway: Prevalence and Sub-Classification in a Cohort of 30 037 Children Born Between 1980 and 1985. *Acta Paediatrica, 87*(3), 291-296.

Summers, J. A., Poston, D., Turnbull, A., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and Measuring Family Quality of Life. *Journal of Intellectual Disability Research*, 49(10), 777-783.

Swanson, D. M. (2007). Ubuntu: An African Contribution to (Re) search for/with a'humble Togetherness'. *Journal of contemporary issues in education*, 2(2), 53-67.

Tassé, M. J., Luckasson, R., & Nygren, M. (2013). American Association for Intellectual and Developmental Disability Proposed Recommendations For ICD-11 and the Condition Previously Known as Mental Retardation. *Intellectual And Developmental Disabilities, 51*(2), 127-131. Doi:10.1352/1934-9556-51.2.127

Tassé, M. J., Luckasson, R., & Schalock, R. L. (2016). The Relation Between Intellectual Functioning and Adaptive Behavior in the Diagnosis of Intellectual Disability. *Intellectual and Developmental Disabilities, 54*(6), 381-390.

Thomas, C (2002). Disability Theory: Key Ideas, Issues and Thinkers. in Barnes, C; Oliver, M Barton, L (Eds). Disability Studies Today. London: *Polity Press.*

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., . . . Yeager, M. H. (2009). Conceptualizing Supports and the Support Needs of People with Intellectual Disability. *Intellectual And Developmental Disabilities, 47*(2), 135-146. Doi:10.1352/1934-9556-47.2.135

Tronto, J., Noddings, N., Buker, E., Sevenhuijsen, S., Bozalek, V., Gouws, A., . . . Robinson, F. (2006). Socializing Care: Feminist Ethics and Public Issues: *Rowman & Littlefield Publishers*.

Turnbull, R., & Stowe, M. J. (2014). Elaborating the AAIDD Public Policy Framework. *Mental Retardation*, 52(1), 1-12.

Turnbull, A. P., Summers, J. A., Lee, S. H., & Kyzar, K. (2007). Conceptualization and Measurement of Family Outcomes Associated with Families of Individuals with Intellectual Disabilities. *Developmental Disabilities Research Reviews*, 13(4), 346-356.

United Nations Convention on the Rights of People with Disabilities. (2006). *Available at the UN Enable website, www.un.org/disabilities.* Accessed on 16th August 2016.

Vanier, J. (2015). Together for the Common Good. *Available from http://togetherforthecommongood.co.uk, Accessed on you tube on 19th September 2017*.

Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of Life and its Measurement: Important Principles and Guidelines. *Journal of Intellectual Disability Research*, 49(10), 707-717.

Wang, M., & Brown, R. (2009). Family Quality of Life: A Framework for Policy and Social Service Provisions to Support Families of Children with Disabilities. *Journal of Family Social Work, 12*(2), 144-167. Doi:10.1080/10522150902874842

Watermeyer, B. (2000). Psychoanalysis and Disability: An Exploration of the Utility of Psychoanalytic Methods and Analyses in the Interrogation of Social Responses to Impairment". *Dissertation, Available at the University of Cape Town Library.* (Accessed in April 2017).

Wehmeyer, M. L., Buntinx, W. H. E., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., Verdugo, M. A., . . . Yeager, M. H. (2008). The Intellectual Disability Construct and Its Relation to Human Functioning. *Intellectual and Developmental Disabilities, 46*(4), 311-318. Doi:10.1352/1934-9556(2008)46[311:TIDCAI]2.0.CO;2

Werner, S., Edwards, M., & Baum, N. T. (2009). Family Quality of Life Before and After Out-of-Home Placement of a Family Member with an Intellectual Disability. *Journal Of Policy and Practice in Intellectual Disabilities*, 6(1), 32-39. Doi:10.1111/J.1741-1130.2008.00196.X

White, N., & Hastings, R. P. (2004). Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 181-190.

WHO. (2001). International Classification of Functioning, Disability and Health: ICF: *World Health Organization.* Available From Www.Who.Int. Accessed On 23rd February 2017.

WHO. (2011). World Report on Disability: *World Health Organization*. Available From Www.Who.Int. Accessed On 23rd February 2017.

Whyte, S. R. (1995). Disability Between Discourse and Experience. *Disability and Culture*, 267-291.

Woodcock, S. (2009). Disability, Diversity, and the Elimination of Human Kinds. *Social Theory and Practice, 35*(2), 251-278.

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2010). Theorizing About Family Quality of Life. Enhancing the Quality of Life of People with Intellectual Disabilities. *Springer*. pp. 241-278.

Zuurmond, M., Nyapera, V., Mwenda, V., Kisia, J., Rono, H., & Palmer, J. (2016). Childhood Disability in Turkana, Kenya: Understanding How Carers Cope in a Complex Humanitarian Setting. *African Journal of Disability*, *5*(1),8.

9 APPENDICES

9.1 Appendix 1: Interview guide for parents/caregivers of people with intellectual disability

Demographic information to be collected

Age of participant:
Gender:
Address/ Residence:
How many members are there in the family?
What do you do?
Who takes main responsibility of care of the person with intellectual disability?

1. **First interview question: According to you, what is a good life in the family?**
2. **Second interview will be a semi structured interview conversation guide for parents/guardians of people with intellectual disability**. *Adapted from the Beach centre family quality of life conversation guide (Beach centre on disability, 2003).*

The goal of the second interview will be to understand the family quality of life by exploring whether family needs are met, family members enjoy their life together as a family and that they have the chance to do things that are important to them. This will serve as a platform from which support needs can be identified. Data from the interviews will be qualitative data.

After discussion in each domain, the following probes will be asked.
Please give an indication of either low, medium or high in the following

a) How important is this to you?
b) How satisfied are you with it?
c) What priority for support would you give this area?

Family interaction

1. Tell me about the time you spend together as a family.
2. What is the situation regarding talking openly with each other in the family?
3. How are problems solved in the family?
4. How do you go about supporting each other to accomplish goals in the family?
5. How is love and care expressed by family members?
6. How are difficulties handled in the family?
7. What are happy moments like in the family?

Parenting

8. What is your experience in helping your children with school work and activities?
9. How do you go about teaching your children how to get along with each other?
10. What is your experience regarding teaching your children how to make good decisions?

11. How do you get to know other people in your children's lives?
12. What is your experience of having time to take care of the individual needs of every child?

Physical/ Material wellbeing

13. What is your experience of transportation?
14. How do you go about taking care of your expenses?
15. What is the situation regarding safety at home, at work or in the community?
16. How do you go about receiving medical care when you need it?
17. How do you go about receiving dental care when you need it?

Emotional wellbeing

18. How do you go about receiving support needed to relieve stress?
19. What is your experience regarding receiving support from friends and others?
20. Tell me about having time to pursue personal interests.
21. What is the situation regarding receiving help from outside the family to take care of individual needs of family members?

Disability-related supports

22. What is the situation of support for your child to make progress at school or in the work place?
23. What is the support situation for your child to make progress at home?
24. How is support organized for your child to make friends?
25. What is the situation of relationships with service providers who work with your child?

Date: ……

Interviewer: …….

9.2 Appendix 2: Interview guide for people with intellectual disability

Demographic information to be collected

Age of participant:
Gender:
Address/ Residence:
Who do you live with?
What do you do?

1. **First interview question: According to you, what is a good life in the family?**
2. **Second interview is a guide with questions for people with intellectual disability to talk about their view of quality of life in the family.** *Adapted from the Beach centre family quality of life conversation guide (Beach centre on disability, 2003).*

The goal of this interview will be to understand the family quality of life by exploring whether family needs are met, family members enjoy their life together as a family and that they have the chance to do things that are important to them. This will serve as a platform from which support needs can be identified. Data to be collected from the interviews will be qualitative data.

After discussion in each domain, the following probes will be asked.
Please give an indication of either

 Low  Medium  High

in the following

a) How important is this to you?
b) How satisfied are you with it?
c) What level of support do you need in this area?

Family interaction

1. How do you spend time together with your family?
2. How open are conversations with each other in the family?
3. Give me some examples of how you solve problems in the family?
4. How do you help each other to do the things that are important to you in the family?
5. Tell me some of the ways that you show each other that you love and care for each other.
6. Tell me how you handle difficult situations in the family?
7. Can you think of some happy moments you have experienced in the family? What were they like to you?

Parenting

Do you have a wife or husband or children? If yes,

8. How do you help your children with school work and activities?
9. How do you teach your children how to get along with each other?
10. What do you teach your children so that they make good decisions?
11. How do you know other people in your children's lives?
12. Tell me about the time you have, to take care of the needs of every child.

Physical/ Material wellbeing

13. What can you say about your experience of transportation? (For example, when using matatu or boda boda).
14. How do you take care of your expenses?
15. Do you feel safe at home, at work or in the community? Tell me more about it.
16. How do you receive medical care when you need it?
17. How do you receive dental care when you need it?

Emotional wellbeing

18. What kind of support do you receive when you are stressed?
19. Tell me about the times you have received support from friends or other people?
20. Could you share with me if you have time to do personal things that you like?
21. What kind of help (if any) do you receive from outside the family to take care of the needs of each family member?

Disability-related supports

22. What support do you receive to make things better and easier for you at school or at work?
23. What support do you receive to make things better and easier for you at home?
24. What support do you have to make it easy for you to make friends?
25. What can you say about relationships you have with people who help you?

Date: …….

Interviewer: ……

9.3 Appendix 3: Information letter and consent form for parents/guardians of people with intellectual disability

Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya

Dear participant,

I wish to give you information about research I am conducting in Nyahururu. I am a student doing a research project at the University of Cape Town requiring me to write a thesis for the award of a Master's degree in Disability Studies. This research aims to find out the family situation of people with intellectual disabilities so that we can identify the needs for support.

The outcome of this study will contribute to my thesis and will later be used to inform people, organizations and institutions that work with people with intellectual disabilities on how to organize support for people with intellectual disability.

We wish to invite your son/daughter with an intellectual disability to participate in the study. He/she will provide us with information based on his/her experience that can be used to improve the lives of people with intellectual disability. If you both agree on his/her participation, we shall plan three visits to your son/daughter. During the first visit we shall get to know each other and identify some of the needs he/she may require for the interview. I will be accompanied by 2 people with intellectual disability who will be helping me collect and record information. We shall explain the study and show some pictures that will be used during the interview to him/her. We shall discuss any concerns there could be about the study and request permission to get involved in the study and to record the discussions. This will take about 30 minutes.

During the second visit we shall ask a question about what your son/daughter considers to be a good life in the family. This will take 20 -30 minutes.

In the third visit, we shall ask 25 questions about different topics of life in the family like relationships, physical, financial, emotional and disability-related matters. The questions will help him/her to think about the situation and how much he/she needs support in it. The answers he/she gives will be recorded and some notes will be taken. Your son's/daughter's name will not be written down and a letter will be used instead. The age, gender, if he/she works, where he/she lives and with whom will be written down. The discussion will last about 45 minutes.

The recorded information and notes will be typed into a computer for analysis. Once we are through with analysis, I will delete the recorded information. The information collected will be used together with that of other people with intellectual disability to understand issues about a good life in the family and where support is needed. The results will be communicated after the analysis where your son/daughter will be invited to a meeting to hear about the outcome if they agree. You will be informed of the date and place well in advance.

The study may benefit your son/ daughter as they may become more aware of their own needs and is also an opportunity for him/her to be listened to. We shall also share the results with people and institutions who follow issues of people with intellectual disability to increase the knowledge on support systems required by people with intellectual disability and their families.

In case your son/daughter experiences emotional difficulty because of sharing, she will be referred for counselling services at St Martin offices.

There is no known risk in participating in this study. Feel free to decide whether to allow your son/daughter to participate in this study or not. There are no consequences for not participating. Your son/daughter is also free to decide whether to participate or not without any consequences. Should there arise disagreement between yourself and your daughter/son about participating, we

shall discuss the matter together to come to an agreeable solution. Your son/daughter will be able to decide not to answer any question or to stop participating at any time without consequences as well.
If you are uncomfortable about anything arising from the research, you can contact Rachael Wanjagua on her telephone number 0721288220 or email at racquelle06@yahoo.com
If you have any questions or concerns about your rights or welfare in taking part in this research, you can also contact the Human Research Ethics Committee in the Faculty of Health Sciences at the University of Cape Town on 021 406 6338.

Thank you for your time and participation

Signed: _____

Rachael Wanjagua
Disability Studies Programme,
Faculty of Health and Rehabilitation Sciences,
University of Cape Town
racquelle06@yahoo.com
Cell: 0721288220

Prof Marc Blockman
Human Research Ethics Committee
University of Cape Town
Marc.blockman@uct.ac.za
Tel: 021 406 6338

Consent Form

I understand that:

- All information in my son/daughter's interview will be not be shared with anyone
- No reports will have his/her name
- My son/daughter can stop at any time
- My son/daughter doesn't have to answer questions that he/she doesn't want to
- My son/daughter will not be paid or given gifts for participating in the study
- I can contact Rachael or the Human Research Ethics Committee if I am worried about something

Do you wish to be called for the feedback session? YES ☐ NO ☐

I give permission for my son/daughter to be involved in this research

Parents/Guardians name: _____

Signed: _____Date: _____ Place: _____

Researcher name: _____

Signed: _____ Date: _____ Place: _____

9.4 Appendix 4: Information letter and consent form for parent/ caregiver participants

Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya

Participant Number: ____

Dear participant,

I wish to invite you to participate in a research I am conducting. I am a student at the University of Cape Town and I'm doing a research for a thesis towards a Masters degree in Disability Studies. This research aims to find out the situation of families of people with intellectual disabilities and the issues they find important for them to have a good life. I hope to understand where they need support for a good family life.
The outcome of this study will be used to inform people and institutions that work with people with intellectual disabilities on how to organize support for people with intellectual disability.
Your information as a parent/caregiver will be useful since you have knowledge about what you think can help to improve the lives of families with people who have intellectual disability.

If you agree to participate, we shall make two visits to you to ask some questions. During the visit, we shall introduce ourselves (myself and a parent of an intellectually disabled person who is assisting me to ask questions) and explain the study in detail. We shall request your permission to ask you the questions which you should decide about freely. There are no consequences if you do not wish to be involved in the research.

The first interview will be a discussion about things that are important to you as a family with an intellectually disabled person. It will take about 30 minutes. On another day, we shall discuss 25 questions about aspects of relationships in the family, parenting, physical, financial, emotional and disability-related matters. This will last about 45 minutes.

You can stop participating in the research any time. You are also allowed not to share about questions you don't feel free to discuss.

We shall record and write down your responses in the discussions with your permission.
We shall not write your name on any research forms to give you privacy. We shall write down your age, gender, where you live, who you live with and address. Your responses together with that of other participants will help us to better understand the situation and support needs of families which have people with intellectual disability. The information gained from discussion will be entered into a computer and analyzed with other results. While details like age, gender, number of households will be included while writing up the thesis, your name will not be revealed. The recordings will be deleted after entering the information in the computer.

You will be given feedback about the outcome of the study together with other participants if you agree. You will be informed about the date and place well in advance.

The study may benefit you as you may become more aware of your own needs as well as offer an opportunity for you to be listened to. In case you experience emotional difficulty because of sharing, you will be referred for counselling services at St Martin offices.

The results of this study will be shared with institutions that follow issues of people with intellectual disability to inform them of appropriate support systems recommended for families of people with intellectual disability.

There is no known risk for participating in this study.
If you are uncomfortable about anything arising from the research, you can contact Rachael Wanjagua on her telephone number 0721288220 or email at racquelle06@yahoo.com
If you have any questions or concerns about your rights or welfare in taking part in this research, you can also contact the Human Research Ethics Committee in the Faculty of Health Sciences at the University of Cape Town on 021 406 6338.
Thank you for your time and participation

Signed: _____

Rachael Wanjagua
Disability Studies Programme,
Faculty of Health Sciences and Rehabilitation Sciences,
University of Cape Town
racquelle06@yahoo.com
Cell: 0721288220

Prof Marc Blockman
Human Research Ethics Committee
University of Cape Town
Marc.blockman@uct.ac.za
Tel: 021 406 6338

Consent Form

I understand that:

- All information in the interview will not be shared with anyone
- The research forms/reports will not have my name
- I can stop at any time
- I don't have to answer questions that I don't want to
- I will not be paid or given gifts for participating in the study
- I can contact Rachael or the Human Research Ethics Committee if I am worried about something

May I record this interview? YES ☐ NO ☐

Do you wish to be called for the feedback session? YES ☐ NO ☐

Participant name: _____

Signed: _____Date: _____ Place: _____

Researcher name: _____

Signed: _____ Date: _____ Place: _____

Witness: _____

Signed: _____ Date: _____ Place: _____

9.5 Appendix 5: Information letter and consent form for people with intellectual disability

Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya

Participant Number: _____

Dear participant,

I wish to invite you to participate in a research project I am conducting. I am a student at the University of Cape Town doing a research project to write a thesis for a Masters in Disability Studies.
The goal of the research is to find out the situation of people with intellectual disabilities and their families in order to identify their support needs.
Your experience and insight as a person with intellectual disability will help us to understand where and how support should be organized.

- If you agree to participate, we shall make three visits to you. During the first visit we shall get to know each other. I will be accompanied by 2 people with intellectual disability who are helping me to ask you questions and record the discussion. We shall explain the study to you and show you some pictures that you will use during the interview.
- We shall ask you for permission to participate in the research as well as from your parent or caregiver. We shall also request permission from you to record the interviews and write down the information we collect. This will take about 30 minutes.
- Feel free to respond the way you like. For example, if you don't want to be involved in the research you can refuse. You can also stop participating any time during the research without requiring to explain. If you feel you don't want to answer some question, you can ask the person asking the questions to continue with other questions.
- During the second visit we shall ask you one general question about what you think is a good life in the family. This may take 20-30 minutes.
- On another day, we shall ask you 25 questions about relationships in the family, parenting, physical, financial, emotional and disability-related matters. The questions are to guide you to think about the situation and how much support you need in it. We shall give you breaks as you require as we ask the questions. Feel free to indicate or speak about any discomfort during the session. The questions will last about 45 minutes.
- We shall record and write some notes when we ask you questions if you give us permission.
- Your name will not be written in any form so that other people may not know that you are the one who gave us the information.
- We shall write down your age, gender, where you live, with whom you live and what you do.
- The information you give us together with that of other participants will be typed into a computer and after we analyze it, I will delete the recording and tear up the notes.
- The information will be analyzed to help us understand the support need for people with intellectual disability.

- This research may help you because: 1) you may become more aware of your own needs. 2). You may feel good that someone is listening to you.
- The results of the research will be used to inform people and institutions that work with people with intellectual disabilities on how to organize support for people with intellectual disability.
- In case you experience emotional difficulty because of sharing, you will be referred for counselling services at St Martin offices.
- You will be given feedback about the results together with other participants if you want. You will be informed about the date and place later.
- There is no known risk to you for participating in this study.

If you are uncomfortable about anything arising from the research, you can contact Rachael Wanjagua on her telephone number 0721288220 or email at racquelle06@yahoo.com or ask your guardian to contact her.
If you have any questions or concerns about your rights or welfare in taking part in this research, you or your guardian can also contact the Human Research Ethics Committee in the Faculty of Health Sciences at the University of Cape Town (see contacts below).
Thank you for your time and participation

Signed: _____

Rachael Wanjagua
Disability Studies Programme,
Faculty of Health and Rehabilitation Sciences,
University of Cape Town
racquelle06@yahoo.com
Cell: 0721288220

Prof Marc Blockman
Human Research Ethics Committee
University of Cape Town
Marc.blockman@uct.ac.za
Tel: 021 406 6338

Consent Form

I understand that:

- All information in the interview will not be shared with anyone
- My name will not be written on any research forms/reports
- I can stop at any time
- I don't have to answer questions that I don't want to
- I will not be paid or given gifts for participating in the study
- I can contact Rachael or the Human Research Ethics Committee if I am worried about something

May I record this interview? YES ☐ NO ☐

Do you wish to be called for the feedback session? YES ☐ NO ☐

Participant name: _____

Signed: _____ Date: _____ Place: _____

Researcher name: _____

Signed: _____ Date: _____ Place: _____

Witness: _____

Signed: _____ Date: _____ Place: _____

9.6 Appendix 6: HREC letter UCT

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.arlefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

30 November 2016

HREC REF: 616/2016

Dr J McKenzie
DHRS
Disability Studies
F-45, OMB

Dear Dr McKenzie

PROJECT TITLE: IDENTIFYING SUPPORT NEEDS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND THEIR FAMILIES THROUGH A FAMILY QUALITY OF LIFE SURVEY IN KENYA (Mphil-candidate-R Wanjagua)

Thank you for your response letter dated 25 November 2016, addressing the issues raised by Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 NOVEMBER 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student; R Wanjagua will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

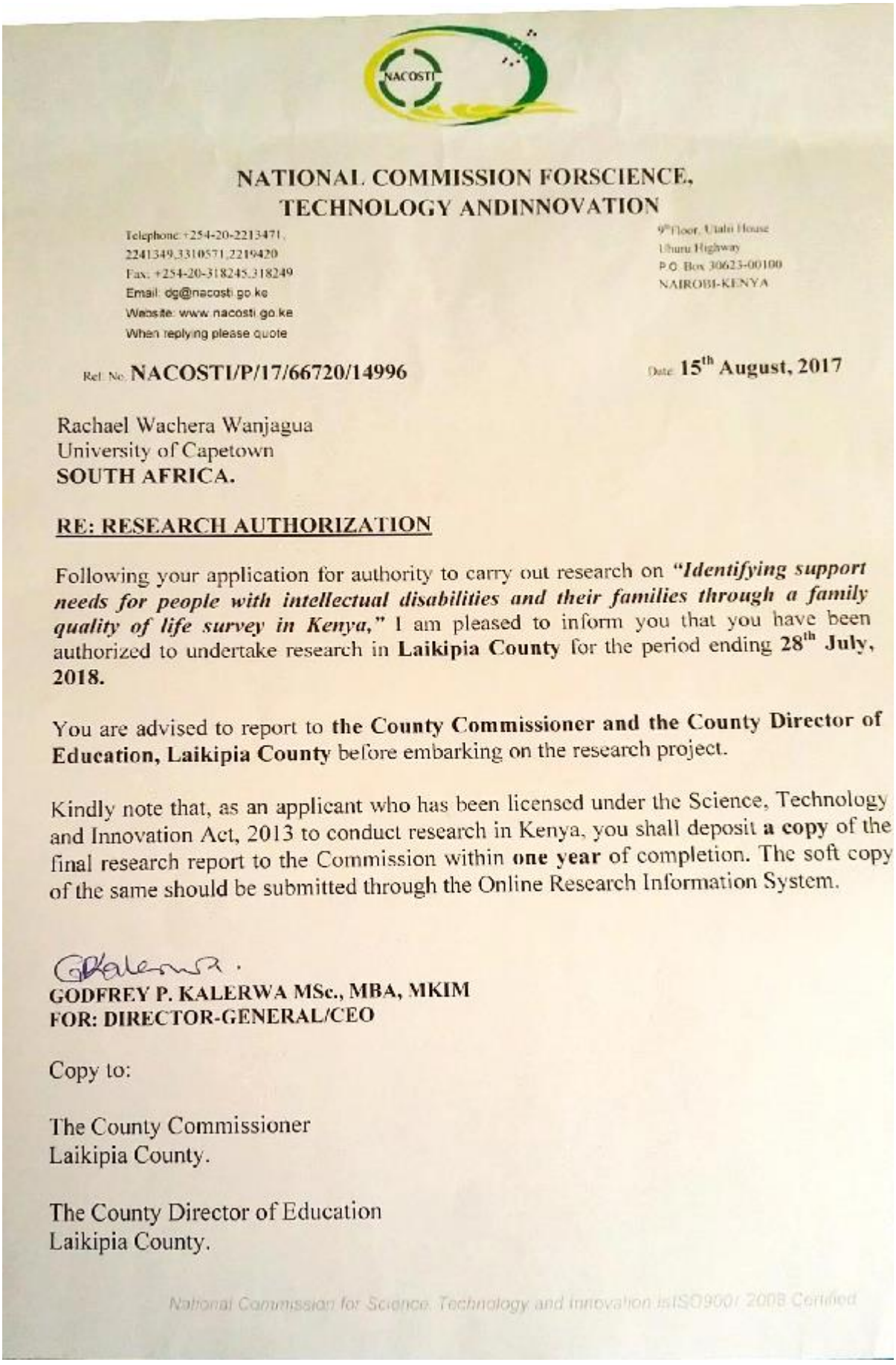
Federal Wide Assurance Number: FWA00001637.

HREC 616/2016

Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 616/2016

9.7 Appendix 7: Research permit NACOSTI



NATIONAL COMMISSION FORSCIENCE,
TECHNOLOGY ANDINNOVATION

Telephone: +254-20-2213471,
2241349,3310571,2219420
Fax: +254-20-318245,318249
Email: dg@nacosti.go.ke
Website: www.nacosti.go.ke
When replying please quote

9th Floor, Utalii House
Uhuru Highway
P.O. Box 30623-00100
NAIROBI-KENYA

Ref. No. **NACOSTI/P/17/66720/14996**

Date **15th August, 2017**

Rachael Wachera Wanjagua
University of Capetown
SOUTH AFRICA.

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on ***"Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya,"*** I am pleased to inform you that you have been authorized to undertake research in **Laikipia County** for the period ending **28th July, 2018.**

You are advised to report to **the County Commissioner and the County Director of Education, Laikipia County** before embarking on the research project.

Kindly note that, as an applicant who has been licensed under the Science, Technology and Innovation Act, 2013 to conduct research in Kenya, you shall deposit **a copy** of the final research report to the Commission within **one year** of completion. The soft copy of the same should be submitted through the Online Research Information System.

GODFREY P. KALERWA MSc., MBA, MKIM
FOR: DIRECTOR-GENERAL/CEO

Copy to:

The County Commissioner
Laikipia County.

The County Director of Education
Laikipia County.

9.8 Appendix 8: Confidentiality binding form

CONFIDENTIALITY BINDING FORM

I……. have been informed about the research on "**Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya"** and are willingly participating in the discussion towards this research.

I understand that there will be other members who will participate in the discussion as researchers, parents or caregivers of people with intellectual disability and people with intellectual disability. These people will be introduced to me by Rachael Wanjagua who is conducting this research for her Masters degree.

I will keep all information that comes to my knowledge within the discussion confidential and will not share or disclose it to anyone after the group discussion.

I will respect the opinions of other members during and after the group discussion.

I have been informed that the information received during the discussion will be kept anonymous and will only be used for purposes of this research.

I do not expect any payment or gifts for participating in the research.

I will only share the things that I feel free to disclose in the discussion.

I am aware that the discussion will be recorded and later deleted when information from the discussion has been retrieved.

I can contact Rachael or the Human Research Ethics Committee if I am worried about something

Participant name: _____

Signed:_____ Date:_____ Place: _____

Researcher name: _____

Signed:_____ Date: _____ Place: _____

Witness: _____

Signed:_____ Date:_____ Place: _____

9.9 Appendix 9: Deputy county commissioner authorisation

THE PRESIDENCY

MINISTRY OF INTERIOR AND COORDINATION OF NATIONAL GOVERNMENT.

Telegram: **"DISTRICTER"**
Telephone: 065 2022100
When replying please quote:

The Deputy County Commissioner
Nyahururu Sub-County -**LAIKIPIA**
P.O. Box 2003-20300
NYAHURURU.

Ref No: **NHR/ED/12/8 VOL.I/69.** and date **16TH OCTOBER, 2017.**
Email –dcnyahururu@yahoo.com
Fax Line -0652022100

Rachael wachera wanjagua
University of capetown
SOUTH AFRICA.

TO WHOM IT MAY CONCERN.

RE: RESEARCH AUTHORIZATION.

Following your authorization by the Natioanal Commission for Science, Technology and Innovation to carry out research on " Identifying support needs for people with intellectual disabilities & their families through a family quality of life survey in Kenya", specifically in Nyahururu Sub-County, I do hereby confirm that the researcher named above has reported to me.

Accord her all the necessary support that she may require to carry out the research which will run for the period ending 28th July, 2018.

FLORA MWORQA
DEPUTY COUNTY COMMISSIONER
NYAHURURU SUB- COUNTY.

9.10 Appendix 10: Sub-county director of education authorisation

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

STATE DEPARTMENT OF EDUCATION

TEL: No.065-20-22272
FAX: No.065-20-22272
Email: deonyahururu@yahoo.com

SUB-COUNTY EDUCATION OFFICE,
NYAHURURU SUB-COUNTY,
LAIKIPIA COUNTY,
P. O. BOX 2280 - 20300,
NYAHURURU.

When replying please quote

REF: NYAH/GEN/82/85

DATE: 16th October, 2017

TO WHOM IT MAY CONCERN

RE: **RESEARCH AUTHORIZATION**
MS. RACHAEL WACHERA WANJAGUA

This is vide your letter from **University of Capetown-South Africa. Ref No. NACOSTI/P/17/66720/14996 dated 15th August, 2017** which refers;

Authority is hereby granted to the above named, to carry out the research activities on "***Identifying support needs for people with intellectual disabilities and their families through a family quality of life survey in Kenya***," in **Laikipia County, Nyahururu Sub-County** for the period ending **28th July, 2018.**

Any assistance accorded to her is appreciated.

FOR SUB COUNTY DIRECTOR OF EDUCATION
NYAHURURU SUB COUNTY (LAIKIPIA COUNTY)
P.O. Box 2280 NYAHURURU
Date.....

ANNASTASIA NJORI
FOR: SUB-COUNTY DIRECTOR OF EDUCATION
NYAHURURU SUB-COUNTY

C C.
COUNTY DIRECTOR OF EDUCATION
LAIKIPIA COUNTY

DEPUTY COUNTY COMMISSIONER
NYAHURURU SUB COUNTY

ISO 9001:2008 CERTIFIED SGS